Injuries, Accidents and Falls in Adults with Learning Disabilities and Their Carers:
A Prospective Cohort Study

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ABSTRACT

Injuries are among the leading causes of death and disability in the world and a major public health concern. Young persons with learning disabilities have a higher rate and different pattern of injuries when compared with young persons without learning disabilities, but little is known regarding adults. The aim of this study was to determine the incidence and types of injuries experienced by a community-based cohort of adults with learning disabilities (n = 511).

Face-to-face interviews were conducted with participants and their carers two years after they had first been recruited into a longitudinal study. The measures were based on those previously used with a large population-based sample (n = 6,104) in the Scottish Health Survey (2003). Results were compared between the adults with learning disabilities and the general population.

Incidence of at least one injury that required medical or nursing attention or treatment in a 12-month period was 20.5% (105), of which 12.1% (62) was due to falls. The standardised incident injury ratio for adults with learning disabilities aged 18 - 64 years, compared with the regional general population aged 18 – 64 years, is 1.63 (95% confidence interval (CI) = 1.55 – 1.71). The types and causes of injuries experienced differed from those found in the general population. Incident injury was predicted by having epilepsy (odds ratio (OR) 1.809), and not having autism (OR 0.153). Incident fall injury was predicted by urinary incontinence (OR 1.976), whilst Down syndrome reduced risk (OR 0.416). Carers of adults with learning disabilities (n = 446) were less likely to experience at least one injury in a 12-month period overall, but they were significantly more likely to experience harmful injury from another person (p = 0.048), and less likely to experience injury through the use of a tool, implement or equipment (p = 0.045), when compared with the regional general population.

These findings are first steps towards understanding the considerable burden of injuries, accidents and falls in the learning disabilities population, and towards informing interventions to prevent injuries and falls in adults with learning disabilities in the future. The types and causes of injury experienced by carers of adults with learning disabilities are also reported for the first time.

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PUBLICATIONS, REPORTS, ORAL PRESENTATIONS AND RESEARCH GRANTS/AWARDS

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With love to my mum and dad, and my friends Margaret and Isobel, for all of the Smokey cat-sitting and laughs out loud.

And finally, this thesis is dedicated to the memory of my cousin, Lorina.

I declare that the contents of this thesis are my own original work.

Signed ……

Date ……

LIST OF ABBREVIATIONS

BMI	Body mass index
CI	Confidence interval (statistical term)
FES	Falls Efficacy Scale (Tinetti et al., 1996)
GP	General Practitioner (family doctor)
HMSO	Her Majesty's Stationery Office
ICD-10	International Classification of Diseases (Tenth Revision) (World Health Organization, 2007)
LD	Learning disabilities
NHIS	National Health Interview Survey (Unites States of America) (United States Department of Health and Human Services)
NHS	National Health Service
OR	Odds ratio (statistical term)
PAS-ADD	Psychiatric Assessment Schedule for Adults with Developmental Disabilities [Checklist] (Moss et al., 1998)
PhD	Doctorate of Philosophy
PPS-LD	Present Psychiatric State for Adults with Learning Disabilities (Cooper et al., 1997b)
SHS 2003	Scottish Health Survey 2003 (Scottish Executive, 2005)
SMR	Standardised mortality rate

T1	Time 1 (baseline) of the larger longitudinal study that the PhD research project was built on to
T2	Time 2 (two-year follow up) of the larger longitudinal study that the PhD research project was built on to

CHAPTER 1:
INTRODUCTION

Literature search: The literature search was conducted using OVID: MedLine and Psychmed and hand searching key epidemiological and learning disabilities journals over the previous 20 years (January 1990 to February 2010).

Overview

This thesis is about the frequency and types of injuries, accidents and falls experienced by adults with learning disabilities. The research itself was borne out of the author's experience of working in a research team/environment, whose research interests were aimed at improving the health and well-being of people with learning disabilities: this research is, continuing and building on these efforts.

This chapter begins by considering injuries, accidents and falls within the public health concerns of the general population, and in particular, falls in older adults in the general population. This is necessary to provide a comprehensive introduction to these events, and to demonstrate that the considerable attention and literature given to these in the general population was drawn on and utilised for the research project contained in this thesis.

The second part of this chapter provides a critical review of the limited published previous research on injuries, accidents and falls in people with learning disabilities, detailing the research gap which the research project contained in this thesis has attempted to address. Finally, a review of the literature on injuries experienced by carers of adults with learning disabilities is presented. This is also an under-researched area, and is addressed in this thesis.

1.1. Injuries, Accidents and Falls: A Public Health Concern

Injuries are among the leading causes of death and disability in the world and a major public health concern. Around five million people (84.4 per 100, 000) die of injuries worldwide each year, and for every person who dies of injuries, several thousand injured persons survive, many of whom are left with permanent disabling sequelae (Krug et al., 2000; World Health Organization, 2002). The external causes of injuries are often categorised as unintentional or intentional. Most road traffic injuries, fire-related injuries, fall injuries, drowning and poisonings are classified as unintentional or accidental; injuries due to assaults, self-inflicted violence, and war are classified as intentional injuries (Baker et al., 1994; Holder et al., 2001; World Health Organization, 2001).

There were 1, 350 deaths and 80, 251 discharges from hospital due to unintentional injury in Scotland in 2001 (30/100, 000 and 16/1, 000 of the general population respectively). Over half a million bed days were taken up with treating the results of injury, which is as many as for heart disease and over half that for all cancer treatment (Scottish Executive, 2003). Whilst statistics provided by the Information Services Division (ISD), which is Scotland's dedicated national organisation for health information and statistics, demonstrate that deaths from unintentional injury have been steadily decreasing since their peak in the 1980s (from 1, 849 in 1985 to 1, 367/1, 350 in 2000/2001 to 1, 283 in 2008), they remain a major cause of death, ill health and disability, with considerable cost to the National Health Service (NHS) (Information Services Division, 2009). Falls are the foremost cause of unintentional injuries and a leading cause of accidental death, after road traffic accidents (Askham et al., 1990; Krug et al., 2000).

1.1.1. Defining Injuries

An injury involves 'a set of circumstances [a cause] and an adverse outcome [consequence], such as physical or mental harm' (Krug et al., 2000).

Physical types and causes of injuries are most commonly defined as all those which are included in the World Health Organization's International Classification of Diseases – Tenth Revision (ICD-10). Types of injuries (e.g. fracture, dislocation, open wound) are classified in the 'Injury and Poisoning' chapter (XIX: S00 – S09) and causes of injury (e.g. motor vehicle collision, fall, sharp objects) are classified in the 'External Causes of Morbidity and Mortality' chapter (XX: V01 – Y98) (Langley & Brenner, 2004; World Health Organization, 2007). The ICD-10 is an international standard for reporting diseases, injuries, and causes of death, and it is widely used by researchers and practitioners to describe, measure and monitor the occurrence of injuries, and to investigate their circumstances of occurrence using an internationally agreed classification. Some examples of the corresponding codes from the ICD-10 classification system are as follows:

- Fracture of the neck of femur (thigh bone) (S72.0) following a fall in/out of bed (W06);
- Wrist or hand burn (T23.0) as a result of touching a hot plate/ring on a cooker (X15); and
- Skull fracture (S02) following a road traffic accident as a pedestrian (V03).

Psychological injuries (e.g. post-traumatic stress disorder) are not covered in the ICD-10 'Injury and Poisoning' chapter, presumably on the basis that the theoretical definition of injury should be confined to those that occur suddenly (Langley & Brenner, 2004). Psychological conditions however, are included separately in the 'Mental and Behavioural Disorders' chapter (V: F00 – F99) (e.g. post traumatic stress disorder, F43.1).

1.1.2. Defining Falls

An early definition of a fall was 'when the vertical line which passes through the centre of mass of the human body comes to lie beyond the support base and correction does not take place in time' (Isaacs et al., 1985). Whilst this definition does describe the mechanical process occurring during a fall, it is not a practical (working) definition which can be used in fall studies, or injury studies which include injuries from falls (Masud et al., 2001). In 1987, Gibson et al. defined a fall as 'an event that results in a person coming to rest inadvertently on the ground or other level, other than as a consequence of sustaining a violent blow, loss of consciousness, or sudden onset of paralysis as in stroke or epileptic seizure'. Since then, many other researchers have been using this or similar definitions of a fall e.g. O'Neill et al., 1996, but it has become increasingly recognised that broader definitions that include e.g. dizziness or loss of consciousness are more appropriate for studies that address cardiovascular and neurological causes of falls (e.g. postural hypotension or epilepsy) (Lord et al., 2007). More recently, the Prevention of Falls Network Europe (ProFane), which is a collaboration of international experts working towards a consensus methodology in this field, have adopted a simpler definition to include falls that occur from *all* causes (Lord et al., 2007). Thus, a fall is defined as 'an unexpected event in which the participants come to rest on the ground, floor, or lower level' (Lamb et al., 2005).

In terms of an operational (working) definition of a fall, Lamb et al. (2005) recommended that use of the above definition with research participants (e.g. persons documenting/reporting their own falls) should consider a lay perspective, whereby participants be asked '[In the past month,] have you had any falls including a slip or trip in which you lost your balance and landed on the floor or ground or lower level?' Key systematic reviews made the same recommendation using the same expert and lay definitions (Hauer et al., 2006; Gillespie et al., 2009).

The Cochrane Review referenced above (Gillespie et al., 2009) also drew attention to previous findings by Zecevic et al. (2006) that a fall has different meanings for different

groups. In this study, older adults (aged 55 years and over) and health care professionals (e.g. doctors, nurses, and occupational therapists) tended to focus on antecedents (e.g. loss of balance) and consequences (e.g. injury) of falling, in terms of what to them constitutes a fall. Thus this also reduces their likelihood of reporting non-injurious (non-consequential) falls, and the opportunity for early intervention. In contrast, researchers described the fall event itself. These findings demonstrate that a working definition of a fall which is appropriate and can be communicated to all groups is necessary for research projects, and in particular those research projects which rely on self-reported data and/or compare fallers and non-fallers.

1.2. Injury Prevention

Since the late 1960s, public health research has shifted from the traditional view of injuries as accidents or random events, and established methods of scientific study for the prevention of injuries (Haddon, 1968). The public health approach to prevention of injuries involves the following four key steps approach:

1. To determine the magnitude, scope, and characteristics of the problem.
2. To identify factors that increase the risk of injury and disability and to determine which factors are potentially modifiable
3. To assess what measures can be taken to prevent the problem, by using information acquired in step 2 to design, pilot-test, and evaluate interventions
4. To implement the most promising interventions on a broad scale (Mercy et al., 1993).

Throughout the past two decades, factors that increase risk have been identified in populations and categorised as intrinsic or extrinsic factors. Intrinsic factors include demographic and biological factors, while extrinsic factors encompass environmental and behavioural factors (World Health Organization, 2008a). The identification of risk factors is key to tailoring interventions to minimise or prevent injury.

1.3. Falls and Older Adults in the General Population

Falls are the foremost cause of unintentional injuries in ‘older adults’. The most frequently used definition for older adults is people aged 65 years and over. Within this age-band, commonly accepted sub-groups are those aged 65 - 74 years, 75 – 84 years, and 85 years and over (Lord et al., 2007). As the examples to follow will demonstrate however, there is

no consistent agreement among studies as to what demographic group constitute older people (Lord et al., 2007).

Older adults of pensionable age (which is 60 years and over for women and 65 years and over for men) comprise 19% of the general population in Scotland [General Register for Scotland, 2006] and 18% in the United Kingdom as a whole [UK Statistics Authority, 2005]. One in three older adults in Scotland/the United Kingdom has a potentially serious fall each year (Health Education Board for Scotland, 2002). In their recent global report on falls in older adults, the World Health Organization (WHO) found that, among community-dwelling older people over 64 years of age, 28% - 35% fall each year. Of those who are 70 years and older, approximately 32% - 42% fall each year. The frequency of falls increases with age and frailty level. Older people who are living in nursing homes fall more often than those who are living in the community. Approximately 30% - 50% of people living in long-term care institutions fall each year, and 40% of them experienced recurrent falls (World Health Organization, 2008a; 2008b).

1.3.1. Fall Risk in Older Adults

Many studies have concentrated their efforts on identifying risk factors for falls in older adults. Graafmans et al. (1996) conducted a study to identify *intrinsic* risk factors for falls and recurrent falls (≥ 2 falls) amongst 354 older adults (aged 70 years and over) over a 28-week assessment period; of whom 126 (36%) reported a fall, and 57 (16%) recurrent falls. They tested mobility impairment i.e. impairment of balance, leg-extension strength or gait, and dizziness upon standing, and found these to be strongly associated with both falls (odds ratios (OR) 2.6 and 2.1 respectively), and with recurrent falls (OR 5.0 and 2.1 respectively). They also found the following risk factors to be strongly associated with recurrent falls only; history of a stroke (OR 3.4), poor mental state (OR 2.4), and postural hypotension (OR 2.0). The results from this study are useful for demonstrating, not only risk profiles (characteristics) of a frail, high risk population, but also intrinsic risk factors which are potentially modifiable e.g. informing interventions to improve mobility.

More recently, Rubenstein et al. (2006a; 2006b) conducted a review of the epidemiology of falls in older adults, and their major causes and risk factors. They identified and summarised twelve large studies which reported incidence of falls, six of which were conducted among institutionalised populations, and six conducted amongst community-based populations. They reported that falls occur in 30% - 60% of older adults (aged 65 years and over) each year, and 10% - 20% of these result in injury, hospitalisation and/or

death. The main causes of falls in older adults were accidents and environment related, and these accounted for 25% to 45% of the falls reported in the series. With regards to the main risk factors for falls they identified and summarised sixteen studies examining multiple risk factors. They reported that risk factors included lower extremity weakness (OR 4.4), history of falls (OR 3.0), gait deficit (OR 2.9), balance deficit (OR 2.9), use of assistive device (OR 2.6), visual deficit (OR 2.5), arthritis (OR 2.4), impaired activities of daily living (ADL) (OR 2.3), depression (OR 2.2), cognitive impairment (OR 1.8), and age 80 years and over (OR 1.7). As these authors demonstrated however, few accidental falls result from environmental hazards alone, but rather 'are the result of the interactions between hazards or hazardous activities and increased individual susceptibility from accumulated effects of age and disease' (Rubenstein, 2006a). In other words, the higher incidence of falls and high susceptibility to fall injury in older adults is due to an interaction between environment and the higher prevalence of clinical diseases and age-related physiological changes (Rubenstein et al., 2006b). The identification of such risk factors, alongside a better understanding of their often complex, multi-factorial nature, has informed published guidelines for assessments, strategies and interventions to prevent falls in older adults, such as the National Institute for Clinical Excellence (NICE) (2004) 'Clinical practice guideline for the assessment and prevention of falls in older people', and the World Health Organization (WHO) (2008b) 'WHO Global Report on Falls Prevention in Older Age'. These guidelines in turn, have built upon the best available evidence.

1.3.2. An Overview of the Main Risk Factors

An overview of the main intrinsic (e.g. demographic and biological) and extrinsic (e.g. behavioural and environmental) factors that increase fall risk in older adults were highlighted in the World Health Organization's (2008a) 'A Global Report on Falls Prevention: Epidemiology of Falls'. These are presented in *table 1.1*., which is followed by a description of each risk factor.

Table 1.1: An Overview of the Main Risk Factors for Falls in Older Adults

Demographic: ▪ Race (being Caucasian) ▪ Low socio-economic status
Biological: ▪ Older age ▪ Sex (being female)
Medical conditions: ▪ Diabetes ▪ Parkinson's disease ▪ Depression ▪ Incontinence (mixed) ▪ Alzheimer's disease
Physical: ▪ Poor gait/balance ▪ Muscle weakness ▪ Visual impairment ▪ Cognitive impairment ▪ Foot problems ▪ Low body mass index (BMI) ▪ Previous falls
Behavioural: ▪ Sedentary behaviour ▪ Medication intake (taking more than four irrespective of type, or certain types e.g. antidepressants or antipsychotics) ▪ Alcohol misuse ▪ Inappropriate shoes ▪ Fear of falling (self-efficacy)
Environmental ▪ E.g. stairs/steps

Source: Adapted from the World Health Organization (2008a), 'A Global Report on Falls Prevention: Epidemiology of Falls'.

Caucasians living in the United States have been found to have a higher risk of falling than other ethnic groups, and their rate of hospitalisation for fall injuries is higher than for Hispanics, Asian/Pacific Islanders, and African-Americans (161 per 100, 000 compared with 43, 35, and 64 per 100, 000 respectively) (Ellis et al., 2001). Low income and poverty are associated with fall risk, due to poor living environment, poor diet, and not being able to access health care services. This is particularly relevant in rural areas and developing countries (Reyes-Ortiz et al., 2004). Fall risk increases with age and frailty and non-fatal fall injuries disproportionately affect women more than men. An example is provided by the first United States study to use national data to quantify gender differences for non-fatal unintentional fall-related injuries among adults aged 65 years and over treated in emergency departments (Stevens & Sodolow, 2005). This study reported the rates of fall injuries for adults aged 85 years and over to be four to five times that of adults aged 65 – 69 years; and of an estimated 1.64 million older adults treated, approximately 1.16 million (70.5%) were women (Stevens & Sogolow, 2005). Although the considerable increase in the prevalence of falls with age and frailty affects both men and women, for the very old (85 years and over), it affects men more than women in particular (Blake et al., 1988; Prudham & Grimley Evans, 1981). Biological factors, such as age and gender, are non-modifiable. Fall risk that increases with age is associated with other changes due to ageing, such as decline of physical, cognitive and affective capacities, and the co-morbidity associated with chronic illnesses (World Health Organization, 2008; page 4).

In terms of medical conditions as risk factors for falls, diabetes mellitus is common in elderly persons. By the age of 75 in the United States for example, 25% of the US population will be affected with the illness (Harris et al., 1998). Diabetes mellitus has been found to be associated with a higher incidence of falls (44%) in community-dwelling older adults (65 years and over) in the United States (Quandt et al., 2006), and identified as an independent fall risk factor among elderly (60 years and over) nursing home residents (Maurer et al., 2005). Falling is also a serious problem in Parkinson's disease, caused by postural instability (Koller et al., 1998). The prevalence of Parkinson's disease also increases with age: in a general elderly population study of 6, 969 persons aged 55 years and over in the Netherlands, prevalence was 1.4%: 0.3% for those aged 55 to 64 years; 1.0% for those 65 to 74; 3.1% for those 75 to 84; 4.3% for those 85 to 94; and 5.0% for those aged 95 years and over (Rijk et al., 1995). Depression or depressive symptoms are common in the elderly: the reported prevalence of mild depressive symptoms among community-dwelling older adults (65 years and over) is between 15% and 20% whilst prevalence of major depressive disorders is between 2% and 5% (Blazer, 1980;

MacDonald, 1997). Urinary incontinence is also common in the elderly: in one group of elderly individuals (aged 60 years and over) 19.3% of women and 10.4% of men report urinary incontinence. Urinary stress incontinence followed by incontinence with urge symptoms (urge or mixed incontinence) is most commonly reported (Schumacher, 2007). Both depression and mixed incontinence are medical conditions associated with an increased risk of falls. For example, in a study of 5, 570 community-dwelling older adults in Italy, a higher prevalence of Parkinson's disease, depression, and urinary incontinence was identified for the group who fell compared to the control group (7.9% versus 6.4%, 68.6% versus 54.9%, and 32.9% versus 30.4% respectively) (Cesari et al., 2002). Senile dementia and cognitive impairment are known as a major risk for falls in older adults, and in particular, Alzheimer's disease (Puisieux et al., 2005). In a longitudinal study of 44 older adults with Alzheimer's type dementia compared with 56 cognitively healthy older adults over a four-year period, falls occurred in 36% versus 11% respectively (Morris et al., 1987). In another longitudinal study of 117 older adults with Alzheimer's disease over a three-year period, of whom initially all but one could walk, 31% reported falls. During follow-up, 50% either fell or became unable to walk, and the fracture rate (69/1000/y) was more than three times the age- and sex- adjusted fracture rate in the general population (Buchner et al., 1987). The most common risk factors for falls in older persons with cognitive impairment and dementia are poor gait/balance, behavioural problems (e.g. wandering), visual problems, being underweight, adverse effects of drugs (e.g. toxic reactions), fear of falling, hypotension, and environmental hazards (Puisiuex et al., 2005).

Tinetti et al (1988) conducted a longitudinal study of 336 community-dwelling older adults (aged 75 years and over) in the United States over a one-year period and 108 subjects (32%) fell at least once during follow-up. These authors identified the following risk factors for falls: cognitive impairment, foot problems, poor gait/balance, and use of sedatives; and 44% of falls occurred in the presence of environmental hazards (e.g. stairs/steps). In another longitudinal study of 568 community-dwelling older American adults (aged 72 years and over) who had fallen over a 36-month follow up period, Tinetti et al (1995a) found female gender, cognitive impairment, and low body mass index (being underweight) to be predisposing independent factors for falls. The environmental risk factor independently associated with serious fall injury was falling on stairs/steps. In the Netherlands, Tromp et al (2001) studied 1, 285 community-dwelling older adults (aged 65 years and over) over a one-year period and 33% fell at least once. These authors found that previous falls, visual impairment, urinary incontinence and the use of benzodiazepines were the strongest predictors of falls. Previous falls, visual impairment, urinary

incontinence, as well as functional limitations, were also the strongest predictors of recurrent falls. Foot problems, poor gait/balance and visual impairment are all self-explanatory as risk factors for falls, in terms diminished functional ability. Muscle weakness (especially lower extremity) has also been identified as a physical risk factor for falls (Moreland et al., 2004). Medications, particularly anti-hypertensive and psychotropic drugs, as well as poly-pharmacy, have consistently been shown to be associated with fall risk in the elderly (e.g. drug reactions or side-effects such as hypotension) (Cumming et al., 1991). It is also reasonable to expect that if a person is underweight, and dietary deficiencies do exist, particularly in calcium and vitamin D, weakness and poor fall recovery will ensue. As dietary calcium and vitamin D are necessary to maintain bone mass and reduce the risk of osteoporosis, there is also a greater risk of fracture as the result of a fall if these are deficient. Excessive alcohol consumption is also associated with an increased risk of falls in older adults (Tuck et al., 2002).

In terms of other behavioural factors, sedentary behaviour increases both the risk of falls and fall-related injuries (Gardner et al, 2000), and exercise programmes are effective interventions to prevent falls in the elderly (Chang et al., 2004). Being physically active controls weight as well as contributing to healthy bones, muscles and joints, and exercise can improve balance, mobility and reaction time (Gardner et al., 2000; Gillespie, 2004). Wearing inappropriate shoes is also associated with fall risk in the elderly e.g. wrong size and/or loose fitting (Tencer et al., 2004).

'Fear of falling', which is the most commonly reported psychological consequence of previous falls, affects an older person's self-efficacy, thus behaviour in terms of e.g. loss of confidence in balance and walking (Arfken et al., 1994). In their Australian study of 528 hospital in-patients (aged 65 years and over), with a 12-month follow up period, Cumming et al. (2000) found that a fear of falling was strongly associated with future falls (adjusted relative risk 2.09, 95% confidence interval (CI) 1.31-3.33), even in older persons who had not fallen recently. In their American study of 2, 212 community-based older adults (aged 65 to 84 years), with a 20-month follow up period, Friedman et al. (2005) found falls at baseline were an independent predictor of developing fear of falling (Odds Ratio (OR) = 1.79; <0.0005), and fear of falling at baseline was a predictor of falling at 20 months (OR = 1.79; <0.0005). In other words, fear of falling was both a consequence of and a predictive risk factor for falls.

1.3.3. Exposure to Risk

Exposure to risk is another feature of the literature on the incidence and risks associated with falls and fall injuries in older adults, and it is sometimes referred to as a third category of risk, alongside intrinsic and extrinsic risk factors (Todd et al., 2004). Exposure to risk refers to the U-shaped association that has been demonstrated in some studies, which have examined the relationship between falls and physical activity, whereby the most inactive and the most active older adults were found to be at the highest risk of falls (Skelton et al, 2001; Graafmans et al., 2003) or fall injury (Tinetti et al., 1994) (Todd et al., 2004). According to Graafmans et al. (2003), this non-linear association is based on contrasting relationships, whereby 'on the one hand physical activity protects against falls by maintaining neuromuscular function, and on the other hand physical activity introduces a higher risk due to higher exposure to risk-bearing situations'. Exposure to risk therefore, demonstrates an increased exposure to the interaction between extrinsic (e.g. risky environmental conditions, such as uneven floors/pavements) and intrinsic (e.g. physical frailty, such as muscle weakness) factors. In order to counter exposure to risk whilst still promoting interventions to prevent or decrease the risk of falls/fall injuries in older adults for example, increased walking but with a walking aid/stick to maintain safety has been recommended before (Graafmans et al, 2003).

1.3.4. Multiple and Common or Shared Risk Factors

It is well-documented that falls are usually multi-factorial, and the more risk factors a person has the more vulnerable they are to falling (Plati et al, 1992). A review of the most effective interventions for the prevention of falls in older adults has illuminated this point, as being based on multi-factorial assessment (Chang et al, 2004).

As depression, incontinence and falls are common and associated conditions in the elderly and impair health and well-being, previous research has concentrated efforts further on the identification of a set of common or shared risk factors for two or more of these conditions, particularly with regards to functional dependence. Functional dependence refers to dependence in activities of daily living, or more simply, decline in daily functioning (Aguero-Torres et al., 1998). For example, in a population-based cohort (n = 927) study of older Americans (aged 72 years and over) with a one-year follow-up, Tinetti et al. (1995b) found the following set of shared risk factors for falls, incontinence, and functional dependence: slow timed chair stands (lower extremity impairment); decreased arm strength (upper arm impairment); decreased vision and hearing (sensory impairment); and either a high anxiety or depression score (affective impairment). And in another cohort study of

283 older adults (60 years and over) in Israel with a one-year follow up, Biderman et al. (2002) identified a common set of factors that increase the risk of both falls and depression: poor self-rated health; poor cognitive status; impaired activities of daily living; two or more primary health care clinic visits in the past month; and slow walking speed (greater than 10 seconds over five metres).

1.3.5. Fall Screening Tools

There are a number of screening tools which have been used in research studies and clinical settings to assess risk of falling among older adults. The following are examples of some of these (Todd et al., 2004):

- The Tinetti balance and gait 24 items scale, which signifies risk if a person has more than six balance and gait abnormalities (Tinetti, 1986).
- The Mobility Interaction Fall Chart, which observes ability to walk and simultaneous interaction with another person/object, and includes a vision test and concentration rating (Lundin-Olsson et al., 2000). This has been found to be predictive of falls when combined with fall history or staff judgement in residential/nursing homes (Todd et al., 2004).
- The Falls Efficacy Scale (FES), which measures a person's confidence in performing a range of daily living activities without falling (Tinetti et al., 1994).

Few screening tools however, have been used or validated widely across different countries, although steps are being taken in that direction. The FES for example, was first developed in the United States, but more recently researchers in the United Kingdom (Yardley et al., 2005) and Europe-wide (Kempen et al., 2007) have been working on an adapted version, the Falls Efficacy Scale – International (FES – I), which now includes relevant items to assess fear/level of confidence in performing more demanding activities (for higher functioning older adults), and social activities (to measure social consequences of falling e.g. embarrassment). Results from these validation studies have so far been promising, demonstrating the suitability of the FES – I for use in cross-sectional (Yardley et al., 2005) and cross-cultural studies across samples in different countries (Kempen et al., 2007), but not its predictive validity.

1.4. Health Inequalities of Adults with Learning Disabilities

1.4.1. What are Learning Disabilities?

Over the past few decades, there has been a research and policy focus on improving the health and well-being of persons with learning disabilities. Learning disabilities, according to the international classification of diseases (World Health Organization, 2007), are defined as an intelligence quotient (IQ) level less than 70, together with impairment of daily living skills or diminished ability, and identification of such life-long problems before the age of 18. More specifically persons with mild learning disabilities have an IQ 50 – 69, moderate 35 - 49, severe 20 – 34, and profound <20. There are multiple causes of learning disabilities. Some people have an identifiable genetic, metabolic, traumatic or infective cause for their learning disabilities such as Down's syndrome, but for the majority of persons with learning disabilities the underlying cause is unknown (Fryers, 1997). There are also some persons with *acquired* learning disabilities, as the result of a traumatic brain injury for example, who develop cognitive impairment and diminished ability in childhood, and are in need of and use learning disabilities care/support services (Hammill, 1990).

1.4.2. Changes in Service Provision

1.4.2.1. Residential Services

Historically, adults with learning disabilities have been one of the most disadvantaged and socially excluded groups in society. Social exclusion has no single definition but refers to the alienation and disenfranchisement of a particular group in society (Bates et al., 2004). Large hospitals provided care and segregation to persons with learning disabilities, and problems of institutionalisation (e.g. overcrowding and poor care standards) were increasingly recognised (Lindsey, 2002). The Victorians conceived the asylums to be 'therapeutic', in that they provided exercise, occupation, fresh air, and fresh vegetables e.g. gardening/growing food, so they were established with good intentions. Society has evolved and we now understand the problems of asylums and value inclusion more. As a result of this, over the past four decades, a policy of resettlement from long stay institutions to care and support in the community has been adopted in the United Kingdom and other high income countries, and realised for the vast majority of adults with learning disabilities who previously lived in institutions (Department of Health and Social Security, 1971; Department of Health, 1992a, 1992b, 1992c, 1995a, 1995b, 1995c, 1995d, 1995e, 1995f, 2002; Scottish Executive, 2000).

The pattern of community-based residential services for adults with learning disabilities has changed dramatically over these years (Mansell et al., 2002). The most recent shift, which has seen greater fragmentation of service provision to a wide-ranging 'mixed economy of welfare' (Wistow et al., 1994), are residential services increasingly made up of small 'ordinary' own tenancy homes for individuals or small groups of individuals on many sites, following the 'staffed housing' or 'supported living' model (Kinsella, 1993; Mansell et al., 1987). This type of service provision is characterised by individualised (person-centred) case management and support planning, and it is based on O'Brien's (1987) five service accomplishments:

- Having a community presence in the 'ordinary places that define community life';
- Having the opportunity to make choices both at the level of day to day decision making and more fundamental life choices;
- Having the opportunity to develop the competence and skills to be able to undertake functional and meaningful activities;
- Being accorded respect;
- Participating in the social life of the community through a growing network of personal relationships.

Adults with learning disabilities who live in staffed housing therefore, are supported to lead ordinary lives (same as everyone else) in their own communities. The principles which underpin this are based upon promoting social inclusion for adults with learning disabilities.

1.4.2.2. Regulation of Residential Services

Residential services for persons with learning disabilities in Scotland are regulated by the national Care Commission. The Care Commission, which was set up with The Regulation of Care (Scotland) Act 2001, registers and annually inspects all the services regulated under the Act. In doing so, the Care Commission takes the National Care Standards (Scottish Executive, 2005) into account. The Care Commission uses these published guidelines to monitor the quality of services and their compliance with the Act and regulations; and to look into complaints or concerns about a service, and be able to determine what necessary action to take. Service-providers use these guidelines on what is expected of them for all aspects of service delivery e.g. from staff induction/training to provide direct care/support to developing relevant policies and procedures at organisational level.

The National Care Standards are based on a set of principles which recognise the service-user's rights to:

- Dignity (e.g. be treated with dignity and respect at all times)
- Privacy (e.g. have privacy and property respected)
- Choice (e.g. make informed choices)
- Safety (e.g. feel safe and secure, including health and well-being)
- Realising potential (e.g. have opportunities to make the most of his/her life)
- Equality and diversity (e.g. have cultural considerations valued and not be subjected to bullying, harassment or discrimination).

The twenty National Care Standards encompass all aspects of care and support, from moving into a home (standards one to six) and settling in (standards seven to eleven), to day-to-day life (standards twelve to nineteen) and moving on (standard twenty). In terms of 'the [home] environment' (standard number four) for example, the potential for/use of equipment and adaptations is covered; and in terms of 'feeling safe and secure' (standard number nine), the service should have 'policies and procedures for managing and assessing risk and recording and reporting accidents and incidents' (Scottish Executive, 2005a).

Another feature of residential care and support services for adults with learning disabilities in Scotland and the rest of the United Kingdom is care management. Care management involves 'co-ordination of the fragmented service delivery system, providing person-centred care and making effective use of resources' (Xie et al., 2008). A person with learning disabilities' care manager, if he or she has one, is a person from a social services department (e.g. social worker) or a community health service (e.g. lead person from a Community and Health Partnership (CHP)) whose role is to oversee, monitor and review the person's overall care/support. Care management arrangements tend to be specific to each locality/local authority.

1.4.3. Health Care Services

Whilst it is true that the majority of persons with learning disabilities have always lived in the community with their families (Lindsey, 2002), the changing pattern of residential services for those who have not has impacted on the provision of specialist/health care services for all adults with learning disabilities who live in the community. (Service provision differs for children and adults with learning disabilities, and children with

learning disabilities continue to use specialist services at paediatric hospitals for their health care) (Schrander-Stumpel et al., 2007).

Learning disabilities hospitals were the main provider of psychiatric and medical services for adults with learning disabilities. The shift towards deinstitutionalisation (hospital closure) has led to: a reduction in specialist learning disabilities training e.g. in nursing; a greater emphasis on primary care as the gateway to health care for adults with learning disabilities; and the redistribution of specialist learning disabilities health care professionals into community-based multi-disciplinary teams (Morgan et al., 2000). Three of the seven principles set out in the Scottish Government's (formerly the Scottish Executive's) review of services for persons with learning disabilities (2000) serve to illustrate the design of community-based health care for adults with learning disabilities:

- People with learning disabilities should be able to use the same local services as everyone else, wherever possible.
- People with learning disabilities should benefit from specialist social, health and educational services.
- People with learning disabilities should have services which take account of their age, abilities and other needs.

Thus, the coordination of health care for adults with learning disabilities who live in the community should be based upon the same for general population (e.g. it should be accessible), with specialist intervention where appropriate, and an increased awareness of the specific health/needs of adults with learning disabilities amongst primary and secondary health care professionals, and non-nursing staff who work in residential services. This latter point is emphasized further in 'Promoting Health, Supporting Inclusion' (Scottish Executive, 2002), which is the national review of the contribution of all nurses and midwives to the care and support of people with learning disabilities. Raising awareness of the specific health needs of adults with learning disabilities is important for the successful delivery of their health and social care services.

1.4.4. Higher Rates of Ill-Health and Different Pattern of Health

The health needs of adults with learning disabilities require specific study, as they differ from the health needs of the general population, with regards to the pattern of need, the types of interventions required, the methods of implementing these, and the required supporting policy. Adults with learning disabilities have a different pattern of health thus health needs than the general population and they experience health inequalities (Cooper et

al., 2004; Scheepers et al., 2005). Health inequality is a generic term used to designate differences, variations, and disparities in the health achievements of individuals and groups which are unfair and unjust (Kawachi et al., 2002).

A number of epidemiological studies have been conducted over recent years, and it is now well-documented that adults with learning disabilities have higher rates of physical and mental health problems, in general as well as within specific learning disabilities conditions (e.g. Down syndrome), than adults *without* learning disabilities in the general population (Howells, 1986; Beange et al., 1995; Smiley et al., 2007). Adults with learning disabilities are more likely to experience for example: gastro-oesophageal reflux disorder (GORD), sensory impairments, osteoporosis, schizophrenia, dementia, dental disease, musculoskeletal problems and nutritional problems (NHS Health Scotland, 2004). Some problem behaviours, such as self-injury, are specific to learning disabilities and may be associated with particular genetic syndromes (e.g. Lesch-Nylan syndrome and Prader-Willi syndrome). Some behavioural phenotypes include psychiatric disorders, such as adults with Down syndrome who are more likely to experience Alzheimer's disease, and at an earlier age (Oliver and Holland, 1986; Holland and Oliver, 1995); and adults with Prader-Willi syndrome have a high prevalence of affective psychoses (Beardsmore et al., 1997).

Conversely, adults with learning disabilities are less likely to experience health problems that are related to smoking, alcohol, and illegal drug/s taking than adults *without* learning disabilities in the general population. In fact the development of health problems directly related to these lifestyle factors in adults with learning disabilities is rare (Lennox & Kerr, 1997). Within the general population, injuries, accidents and falls are associated with alcohol and drug use.

1.4.4.1. Different Causes of Death

The commonest causes of death also differ for people with learning disabilities. For the general population, the leading cause of death is cancer, followed by ischaemic heart disease, then cerebrovascular disease. For people with learning disabilities, respiratory disease followed by cardiovascular disease related to congenital heart disease are the leading causes of death, with cancer ranked lower. Their pattern of cancers is also different, with lower rates of lung, prostate and urinary tract cancers, and higher rates of oesophageal, stomach, and gall bladder cancer and leukaemia (Hollins, 1998; NHS Health Scotland, 2004).

1.4.4.2. Epilepsy

The estimated prevalence of epilepsy in persons with learning disabilities is 25% (NHS Health Scotland, 2004). This compares with a prevalence of 0.5% in the general population (Lhatoo et al., 2001). In other words, adults with learning disabilities are about 50 times more likely to have epilepsy than adults *without* learning disabilities in the general population. Given this much higher rate, it will be important to consider epileptic seizures as a potential cause of falls and fall injuries in adults with learning disabilities.

1.4.4.3. Lower Life Expectancy

The life expectancy of people with learning disabilities has been shown to be increasing steadily over the past four or five decades, as a result of for example, improved socioeconomic conditions, intensive neonatal care, improving access to health care, and increasing survival (Carter et al., 1983; Patja et al., 2000). Despite this however, the life expectancy for people with learning disabilities remains lower than for the rest of the population.

Standardized mortality rate (SMR) is the ratio of the number of observed deaths in a specified group to the number expected, where the number expected reflects the frequency of deaths within the larger population from which the study sample has been taken. If the SMR ratio is equal to 1.0, then this means that the number of observed deaths equals that of expected deaths. If higher than 1.0, then there is a higher number of deaths than expected (Everitt, 2002).

In a study of 1, 478 children and adults with learning disabilities living in a province in Sweden, 124 (8.4%) deaths occurred over a seven-year period (Forsgren et al., 1996). The number of deaths for this cohort were compared with the number for the general population in the study area, and the SMR for the persons with learning disabilities was found to be 1.6 (95% confidence interval (CI) 1.3 – 2.01). The SMR increased significantly for those persons with learning disabilities *and* epilepsy, at 5.0 (CI 3.3 – 7.5), and those persons with learning disabilities, epilepsy *and* cerebral palsy, at 5.8 (CI 3.4 – 9.7). In the United States, Decoufle et al. (2002) studied the deaths of 30 (1.9%) children and young adults with learning disabilities (aged 10-19 years) in a population-based cohort (n = 1, 584) over a ten year period and found the SMR to be 3.3 (CI 2.1 – 5.01). Despite their restricted sample, in terms of age range, these authors also found SMRs to be higher for children and young adults with learning disabilities *and* other disabilities, namely cerebral palsy 11.4 (CI 6.2 – 19.1), epilepsy 5.8 (CI 3.5 – 9.1), hearing impairment 5.0 (CI 1.0 –

14.5), and visual impairment 17.1 (CI 6.3 – 37.2). SMR was higher for those with severe learning disabilities 8.4 (CI 4.8 – 13.6) compared with those with mild learning disabilities. A ten-year study of a population-derived cohort of 693 people with learning disabilities in Australia found the SMR to be 4.9 (CI 3.4 – 6.4) across all levels of learning disabilities (Durvasula et al., 2002). In summary, reported SMRs for people with learning disabilities range from between 1.6 and 4.9, with increased SMRs for people with learning disabilities *and* other disabilities, for example, learning disabilities *and* epilepsy ranging from between 5.0 – 5.8, with a higher SMR or 8.4 for those with severe learning disabilities.

The first population-based study to measure the extent of excess mortality in people with learning disabilities in the United Kingdom was conducted by Tyrer et al (2007). They compared 2, 436 adults with moderate to profound learning disabilities (aged 20 years and over) living in the geographical regions of Leicestershire and Rutland with the general population in the same study area and age range. Four hundred and nine (16.8%) of the adults with learning disabilities died over a twelve year period, which was three times higher than for the general population. Had persons with mild learning disabilities been included in this study however, the mortality rate would have been lower. Patja et al. (2000) provided the only nation-wide study of life expectancy of people with learning disabilities to date, in Finland. They demonstrated that the life expectancy for people with learning disabilities diminishes as the level of ability decreases, with the proportion of expected life lost for people with profound learning disabilities in their study being >20%, and the life expectancy of people with mild learning disabilities is closer to that of the general population.

1.4.4.4 Unmet Health Needs and Barriers

The lower life expectancy of adults with learning disabilities is in part because adults with learning disabilities have a higher level of health needs than the general population and these health needs are often unrecognised or unmet (Tyrer et al., 2007). One of the reasons for this is the lack of awareness of the health needs of adults with learning disabilities amongst those who are responsible for planning (e.g. policy-makers – see next section) and delivering their health and residential care. For example: in primary health care, general practitioners (GPs) and practice nurses receive no routine special training in learning disabilities and they may or may not be aware of the specialist learning disabilities team in their area; and it is non-nursing support workers, rather than learning disabilities nurses, who now provide residential care in the form of supported living. Adults with learning disabilities also experience other health inequalities in the form of barriers to accessing

health care. For example, some adults with learning disabilities have special communication needs and experience a lack of accessible information (e.g. communication in non-written format using pictures or symbols) to be able to attend and understand medical advice/instructions given at appointments; lack of access for wheelchair-users; and even exclusion from some health promotion/monitoring initiatives e.g. cervical or breast screening because they are presumed not to be able to take part and/or, as in the former example, not sexually active. All of these factors contribute to the ongoing health inequalities experienced by adults with learning disabilities (Cooper et al., 2004; NHS Health Scotland, 2004; Scheepers et al, 2005).

1.4.4.5. Reducing Health Inequalities

Reducing health inequalities has been the focus of policy. For example, reducing health inequalities experienced by people from ethnic minorities or those living in poverty or areas of social deprivation. Current strategies however, are based on priorities and the health needs of the general population (e.g. the commonest causes of death for the general population as a whole) (Aldrich et al., 2003). As adults with learning disabilities have a different pattern of health needs, and their causes of death differ, most current policies and public health initiatives will widen rather than close their health inequality gap by:

- Only addressing the prevention and/or management of health problems which are not as commonly experienced by adults with learning disabilities (e.g. smoking related).
- Not addressing the prevention and/or management of health problems which are more commonly experienced by adults with learning disabilities, in terms of unmet health needs.
- Not paying attention to reasonable adjustments or supports that can be made so that adults with learning disabilities equally benefit (e.g. improving accessibility of services).

The extent of inequality is also greater for adults with learning disabilities than for other excluded groups (e.g. ethnic minorities or those who live in poverty or areas of social deprivation), as demonstrated by the standardised mortality ratio for persons with learning disabilities (section 1.4.4.3.) (Cooper et al., 2004; Graham, 2004; Davey Smith et al., 2000).

The population of adults with learning disabilities requires specifically targeted public health interventions to reduce these inequalities. To achieve this, we must first better understand the extent and type of inequalities, and contributory factors.

1.5. Injury Rates in Young People with Learning Disabilities

Having presented the context, this introduction now focuses on injuries, falls and other accidents specifically as experienced by people with learning disabilities. Research from the United States of America (US) and Australia has demonstrated that young people with learning disabilities have higher rates of injuries when compared with the general population of young people (Dunne et al., 1993; Sherrard et al., 2001a; Slayter et al, 2006).

An American study included 1, 060 children with learning disabilities and their controls (matched for age and gender), and 963 children with chronic illness and their controls, all aged birth to 17 years (Dunne et al., 1993). Results were based on analysis of the US 1988 National Health Interview Survey (NHIS) (United States Department of Health and Human Services, 1988). The 1988 NHIS collected ill/health data through face-to-face interviews (based on 12-month recall) from over ten thousand infants, children and adults in households across the United States. They found that children with learning disabilities had higher injury rates than did their controls, but children with chronic illness did not (Dunne et al., 1993). These authors suggested that different patterns of injury between the groups may have been due to both impaired functioning for the children with learning disabilities and over-protection with decreased exposure to risk for the children with chronic illness. There was no data available on related causes of injury, circumstances and contributory factors.

The main limitation of this study was its design, which attempted to identify children and young people with learning disabilities from secondary analyses of general population data. The identification of persons with learning disabilities in the general population can be problematic, if there is no set criteria for the identification of learning disabilities, or if data on learning disabilities conditions/diagnosis was not collected (Wen, 1997). The results from this study were based on analysis of the 1988 NHIS. This *pre-dates* the Americans with Disabilities Act (ADA) in 1990, which saw the introduction of the NHIS – Disability Supplement in 1994/1995, and a more comprehensive set of questions/criteria for the identification of persons with learning disabilities in the sample (Larson et al., 2001).

In Australia, Sherrard et al. published results from their longitudinal study of 465 young Australians with learning disabilities aged 5 – 29 years, including injury incidence (Sherrard et al., 2001a) and risk factors for injury (Sherrard et al., 2002). They also

subsequently reviewed the evidence for injury prevention in both learning disabilities and general populations (Sherrard et al., 2004). This was the first population-based study to investigate injuries in young people with learning disabilities, and it was these papers which informed this subsequent PhD research project investigating injuries in adults with learning disabilities.

In Sherrard et al.'s (2001a) study of 257 young Australians with learning disabilities, 147 of the young persons with learning disabilities (group 1, aged 15 – 29 years) had been recruited as part of a longitudinal cohort six years earlier, into a programme examining emotional and behavioural problems in young persons with learning disabilities. A further 110 children with learning disabilities (group 2, aged 5 – 14 years) had been included to supplement the sample. Both groups had been recruited into the programme from the same geographical region, but group 2 had not participated at the first point in time, six years earlier. Group 1 comprised a sub-sample of the longitudinal cohort (n = 465), which was restricted to the largest geographical region it covered. Data was collected from carers via postal questionnaires, and medical record data was collected from audits conducted by hospitals and general practitioners. State registries were also accessed to provide information concerning deaths and inquests for the study group. Comparative age matched general population medical injury data were extracted from national statistics provided by the Australian National Injury Surveillance Unit (NISU) mortality collection, and the same audits conducted by hospitals and general practitioners which were used for the study group. Sherrard et al. (2001a) reported the annual injury mortality rate to be 150/100, 000 persons and the annual injury morbidity rate to be 55.6/1, 000 persons. This gives Australian standardised unintentional injury mortality and morbidity ratios of 8 and 2 respectively. Major contributors to this excess were falls (defined as fall injury presentations to hospital accident and emergency departments requiring subsequent hospitalisation), asphyxia (defined as both non-fatal and fatal injury), and drowning (defined as both non-fatal, as in near drowning, and fatal injury), with the majority occurring at home, unlike in the general population.

Sherrard et al. (2002) then utilised medical records and carer report data collected for 465 young persons with learning disabilities who had participated in the longitudinal study/programme at both points in time, six years apart, to investigate biological, psychological and social factors independently predictive of incident injury. Risk was found to be increased in young people who additionally have the presence of psychopathology (emotional and behavioural problems) (odds ratio (OR) = 3.4), or

epilepsy (OR = 2.4), or an overly sociable temperament (OR = 2.2), whilst being blind, deaf or immobile reduced risk. In their review of the evidence, Sherrard et al. (2004) suggested that injury prevention strategies for children in the general population require design modification if they are to be effective for children with learning disabilities. For example, one suggestion was to modify approaches to environmental safety which are more usually designed for pre-school children, so that they can also be used to the advantage of older children with learning disabilities. The provision of more information and support to parents/carers e.g. home visits, and improved management of psychopathology and epilepsy were also suggested (Sherrard et al., 2004).

In a study published after this thesis commenced, Slayter et al. (2006) in the United States utilised Medicaid's dataset to undertake a secondary analysis of injury data from in-patient, out-patient, and long-term care settings, and to determine injury prevalence among young people with learning disabilities. Medicaid is a public health care insurance programme available for people with low income, and certain other eligible groups. One year data on 8.4 million Medicaid-eligible young people aged 1 to 20 years from across 26 states was examined, of whom 0.6% (n = 49, 775) had learning disabilities. In that year, 1999, 37/100 young persons with learning disabilities had been treated for an injury compared to 23/100 young persons without learning disabilities in the same data set. In terms of injury types, the young persons with learning disabilities were notably more likely to be have been treated for poisoning (OR = 3.72), foreign body injury (OR = 3.45), dislocation of a joint (OR = 2.74), or an internal injury (OR = 2.49). The higher prevalence of treated injury per 100 young people with learning disabilities was less than the two-fold increase expected from Sherrard et al.'s (2001a) findings. However, the results from this particular study were based on an eligible sample of young persons with and without learning disabilities who had/not made an insurance claim to Medicaid only, and are thus not representative of the USA population, nor generalisable to other populations. Additionally, data on serious injuries from road traffic accidents would not have been collected if they had been covered by automobile insurance claims instead; and minor injuries of persons with learning disabilities treated by residential care/support staff may not have been reported either.

1.6. Injury Rates in Adults with Learning Disabilities

Previous study on injuries and falls among adults with learning disabilities is limited. An overview of thirteen previous studies that have been conducted is presented in *table 1.2.*, with a discussion of each of their findings and limitations to follow. Only six of these studies comprised samples which are exclusively of adults with learning disabilities aged 16 years and over.

Table 1.2: An Overview of Previous Studies on Injuries and Falls among Adults with Learning Disabilities (four pages)

Year	Author et al	Age group In years	Sample size	Levels of LDs	Setting/ Participants and Methods	Results	Country
1987	Dupont et al.	15 years and over	7, 134 national population	Borderline to Mild	Community/population-based. Analysis of 1976 – 1984 national register	Accidents were reported to be a more common cause of death for persons with learning disabilities, when compared with the general population.	Denmark
1998	Strauss et al.	All ages	520 deaths of State population	Mild - Profound	Community/population-based. Rates and causes of deaths between 1981 and 1995 using database of all persons who received services from the State	The study population was at a higher risk of deaths from pedestrian accidents, falls, and fires compared with the general population, and at a lower risk of deaths from murder, suicide and poisonings.	United States
1999	Lohiya et al.	Five years and under - 45 years and over	994 (47 aged 17 years and under, and 947 aged 18 years and over)	Profound/ Non-profound	Residential home. Review of records of all persons with learning disabilities who had experienced a fracture during the preceding 3.5 years.	11.5% experienced at least one fracture in the preceding 3.5 years. The observed fracture rate was 1.7 times greater than the fracture rate for the United States general population. Falls were related to 23% of fractures.	United States
2001	Hsieh et al.	30 years and over	268	Mild - Profound	Nursing home residents over a 12-month period. Interviews with care staff and review of clients	11% sustained injuries over a 12-month period, 50% of which were caused by falls. Risk factors were identified	United States

					records.	for falls (older age, ambulatory, and frequency of epileptic seizures) and fall injuries (frequency of epileptic seizures, destructive behaviours, and anti-psychotic drugs).	
2001	Community Services Commission	Birth - 24 years, and 25 years and over	31 children and young people and 180 adults	Mild - Profound	Reported deaths of 211 children/adults with learning disabilities in government residential care. Review of causes and circumstances of deaths reported between 1991 and 1998: care records; and health/medical/coroners reports.	Deaths due to drowning, falls, and self-harm were more common for the persons with learning disabilities, when compared with deaths reported for the general population.	Australia
2001	Grant et al.	18 years and over	114	Mild - Profound	One organisation providing residential care/supported group living Computerised medical records and incident reports were reviewed for non-injurious and injurious falls over a 5-year period.	70% of adults fell at least once over the study period. Co-morbidity was found to be significantly associated with falls.	Canada
2001a; 2002	Sherrard et al.	5 - 29 years	A sub-sample of 147 aged (15 – 29 years) from a longitudinal cohort (n = 465)	Mild - Profound	Reported fatal and non-fatal injuries experienced by young persons with learning disabilities, compared with the general	Reported standardised unintentional injury mortality and morbidity ratios of 8 and 2 respectively. Risk	Australia

			recruited 6 years before, plus 110 aged (5 – 14 years)		population. Data was collected from carers via postal questionnaires, medical records, and primary and secondary health care audits.	factors for incident injury were epilepsy, psychopathology, and overly sociable temperament. Being blind, deaf or immobile reduced risk.	
2002	Donald Beasley Institute	18 years and over	~700	Mild - Profound	Users of 13 residential and/or vocational services in the geographical areas of Otago and Southland. Review of written records of injury incidents over a 12-month period.	36% experienced at least one injury in the 12-month period.14.3% experienced at least one fall. 31% of injuries (n = 594 injuries) reported were falls-related, with falls accounting for 45% of the serious injuries incurred.	New Zealand
2002	Durvasula et al.	10 – 64 years	693	Mild - Profound	Community/population-based, longitudinal in design. Review of incidence and causes of deaths in study population between 1989 and 1999: search of state registrar's database and death certificates obtained.	The SMR for the study population was found to be 4.9 (CI 3.4 – 6.4). The common causes of death differed from those of the general population.	Australia
2005	Konarski et al.	14 – 81 years	384 at years 1 and 2; 355 at year 3	Mild to Profound (over 90% severe or profound)	Retrospective (years 1 and 2) and prospective (year 3) study of young persons and adults with learning disabilities living in an intermediate care facility. Testing the reliability of a risk of injury assessment	Results demonstrate a risk of injury assessment tool which has promise for use with young persons and adults with learning disabilities.	United States

					tool.		
2006	Wagemans et al.	All ages	338 adults with learning disabilities who live in campus-based residential care	Mild to Profound	People living in a campus-based residential care. Falls data was collected by nursing staff on a weekly basis over a 33-month study period. Personal health information was also collected.	61% of the adults had fallen at least once during the study period, of whom 29% had experienced repeated falls (≥ 3). Factors significantly associated with falls incidence were epilepsy, antiepileptic drugs, previous fractures, ambulatory, ageing, visual impairment, and hemiplegia.	Netherlands
2007	Hale et al.	21 – 81 years	20	Profound	Convenience sample with a history of falling, recruited from local residential/vocational services. Physical assessment of balance/walking capabilities at a physiotherapy clinic.	Routine tests were unsuitable for use with adults with profound learning disabilities. The only commonality found between participants was their abnormal gait patterns.	New Zealand
2009	Chiba et al.	20 – 69 years	144	Mild to Profound	Congregate care home residents, 3-month recall. Data collected from medical care records and care staff incident reports. Sub-sample (n = 41) had balance assessed by a neurologist at three different points in time, one year apart.	28.5% had experienced two or more falls in the preceding three months, and associated risk factors for falls were identified; advancing age, epilepsy, and paretic conditions.	Japan

One study reported that 11% (30 people) of 268 participants (aged 30 years and over) living in large congregate care nursing homes in the United States had sustained injuries that required treatment from a physician over a twelve-month period, 50% of which had been caused by falls (Hsieh et al., 2001). Participants with epilepsy who experienced seizures on a monthly basis (OR = 6.94), destructive behaviour (OR = 1.54), or who took antipsychotics drugs (OR = 2.37) were found to have the highest risk of injuries. Participants who were aged 70 years or over (OR = 10.63), ambulatory (OR = 9.47), and with epilepsy who experienced seizures less than once a month (OR = 5.51) were found to have the highest risk of fall injuries. Data was collected through interviews with nursing home staff and reviews of residents' records. Baseline data were collected in 1989/1990, and follow up data (including data on injuries) were collected in 1991/1992. No significant baseline differences in gender, age, or level of learning disabilities were found between those who had experienced injury and those who had not experienced injury in the twelve months prior to follow up. The main limitation of this study was the biased sampling, resulting in findings that are not generalisable. Additionally, the study did not utilise health measures, nor explore environmental or staffing factors to identify potentially modifiable associated risk factors.

Grant et al. (2001) conducted a study to describe the falls and fall injuries experienced by 114 ambulatory adults with learning disabilities aged 18 years and over, over a 5-year study period. All of the adults with learning disabilities were living in residential or institutional care provided by the same service-provider in the Kingston and Eastern Ontario region in Canada, and data was collected from the service-provider's computerised medical records and incident reports on non-injurious and injurious falls. There were a total of 273 reported falls in this cohort. Seven out of every ten persons with learning disabilities within this cohort experienced at least one fall over the study period (70%), and 79% of these falls resulted in an injury. Only co-morbid symptoms ($p = 0.04$) was found to be significantly associated with injurious falls, whilst the following factors were not; gender ($p = 0.61$), level of learning disabilities ($p = 0.85$), age ($p = 0.64$), physical/sensory impairment ($p = 0.80$), place of residence (group home or institution) ($p = 0.52$), and whether or not the person's freedom of movement was restricted (living in a locked ward) ($p = 0.22$). Co-morbid symptoms ($p = 0.003$) and restricted freedom of movement ($p = 0.005$) were also found to be significantly associated with falls incidence, which the other factors tested were not; gender ($p = 0.83$), level of learning disabilities ($p = 0.86$), age ($p = 0.76$), physical/sensory impairment ($p = 0.92$), and place of residence ($p = 0.89$).

Grant et al.'s (2001) study did attempt to investigate some of the potential risk factors for non-injurious and injurious falls in this cohort of adults with learning disabilities, but the study itself does have a number of limitations and the authors' reporting of the results is questionable. Firstly, the cohort was restricted to ambulatory adults with learning disabilities in supported living or residential care settings only, thus was not representative, as non-ambulatory adults with learning disabilities, and/or those who live at home on their own or with their family, were not included. Secondly, the time period for follow-up varied between the individuals with learning disabilities over the study period, ranging from between 3 months to 5 years, with a mean follow-up time of 4 years and 5 months. The variation in time period across individuals is not clearly explained in this study, and the results are confusing. The authors do not state for example, the size of the sample at the start of the study and whether or not the variation in time period across individuals was due to residents being discharged from the institution or admitted. Thirdly, a lack of personal information/details in individual case reports was acknowledged by the authors as hindering their ability to describe the types and patterns of injury more completely. Whether the factors investigated were predictive or associated is also unclear, e.g. it is unclear whether the personal health data was collected at the start or at the end of the study period. The authors also reported that 'large numbers of the sample' (actual figure not reported) relocated from an institutional setting where they had lived for decades to several group homes across the region during the study period. Such a significant life event as residential relocation for ex-institution adults with learning disabilities may well have impacted on these results e.g. more falls could occur as a result of having to adjust to their new environments. The authors did acknowledge this, but they failed to take this into consideration at the time of conducting their research, because they did not report falls and fall injuries for individuals pre- and post-residential relocation.

Dupont et al. (1987) utilised the national Danish Register, for the period 1976 – 1984, to provide information on mortality, life expectancy and causes of death of 7, 134 adults with mild learning disabilities. The Danish Civil Registration System, aided by the unique personal identification number assigned to each Danish resident, has registered demographic, residence, medical, and kinship information on all residents residing in Denmark (Oyen et al., 2009). Accidents were reported to be a more common cause of death for persons with mild learning disabilities compared with the general population, particularly for men aged 15 – 64 years (Dupont et al., 1987). Associated factors were not studied. Only causes of deaths for adults with ICD8 310 (borderline learning disabilities)

and 311 (mild learning disabilities) diagnoses were examined, not causes of deaths for all adults with learning disabilities (1CD8 310 – 315 diagnoses).

In Australia, a service audit of deaths of 211 children and adults with learning disabilities (31, 15% and 180, 85% respectively) who had lived in government residential care in New South Wales between 1991 and 1998 found that deaths due to drowning (6 persons, 2.8%), falls (5 persons, 2.4%), and self-harm (actual figure not given) were more common than for the general population (Community Services Commission, 2001). Deaths which had occurred in non-government residential services were not reported, thus not examined. The audit concluded that in some cases the contributory factors could have been preventable e.g. with improved bathing practises.

In a population-based longitudinal study of 693 people with learning disabilities in the Lower North Shore (LNS) area of Sydney, New South Wales, Durvasula et al. (2002) found that 40 persons with learning disabilities had died during the period 1989 – 1999. The population of learning disabilities in the LNS area had been identified during that period in a prevalence study by Beange et al. (1996), whereby ascertainment was made via contact with all voluntary and government agencies providing services for people with learning disabilities in the area. Information on the causes and circumstances of these deaths was collected from death certificates, coroner records, hospital medical records, residential care home files, and family members. The number of deaths over the 10-year period was compared with the same for the LNS general population, and the standardised mortality ratio for the study population was found to be 4.9 (95% confidence interval (CI), 3.4 – 6.4). Deaths from external causes (harm, self-harm and accidents) were common for the study population (8 deaths, 20%) and the LNS general population (21%), but the types of deaths from external causes/injury were different between the two groups: while suicide and road traffic accidents accounted for the vast majority of these deaths in the LNS population, the causes were more variable in the study population (e.g. drowning, burns, drug toxicity and choking), and there were no suicides.

A large Californian study of persons with learning disabilities who received any services from the State, investigated external causes of death (Strauss et al., 1998). There were 520 such deaths during 1981 – 1995. They found that people with learning disabilities were at a lower risk of murder, suicide, and poisonings (standardised mortality ratios, 0.31 – 0.68), but at a higher risk of pedestrian accidents, falls, fires, and especially, drowning (standardised mortality ratio = 6.22), when compared with the general Californian

population. The studies of Strauss et al. (1998) and Durvasula et al. (2002) provide information on fatal accidents, but they do not provide us with any information on non-fatal accidents.

Research on injuries experienced by adults with learning disabilities (aged 18 years and over) who used thirteen residential and/or vocational services in the geographical areas of Otago and Southland was conducted by the Donald Beasley Institute (2002), on behalf of the Accident Compensation Corporation (ACC) in New Zealand. From their review of injury incidents recorded routinely by various care/support staff in these 13 service agencies over a 12-month period, they reported that of the estimated number of 700 adults with learning disabilities in total, 255 (36%) had experienced a total number of 594 injuries (some people had more than one injury). The two most common causes of the 594 injuries were struck by/against (e.g. banging into an object/furniture) for 261 (44%); and falls for 184 (31%). One hundred participants (14%) had experienced at least one fall in the 12-month period. Most injuries were followed by on-site first aid (273; 46%), or no treatment (154; 27%). Of the total number of injuries reported, 65 (11%) had resulted in medical attention or treatment. They did not report the number or proportion of people with learning disabilities who had injuries resulting in medical attention or treatment.

In addition to failure to report the proportion of people with learning disabilities who had injuries requiring medical attention or treatment, the study has a number of other limitations. The distinctions between injuries that required medical attention or treatment, on-site first aid, and no treatment are confusing. It is unclear on whose judgement these distinctions were made, and the extent to which these were due to not being detected, thus treated, at the time they occurred. They appear to be based on the individual perspectives of a large number of staff, with no standardised criteria. The results are also limited because, although they concern a community-based sample of adults with learning disabilities who use residential and/or vocational services, only injuries that occurred in or around these services were recorded. The results did not include for example, any injuries that the adults with learning disabilities who used vocational services only may have incurred at home, or when they were out and about in their own leisure time. Hence, the majority of injuries were reported to have occurred in residential settings 297 (50%) and sheltered workshops 160 (27%). The authors stated that few injuries occurred in public places away from the learning disabilities services, but provide little supporting evidence. The report relied on routinely collected information from incident reports, so there is also likely to be an element of under-reporting due to lost or mislaid incident reports or failure

to complete incident reports. Additionally, the authors of the report state that there was great variation in the systems for recording and reporting injury incidents across and within agencies. These findings are useful for highlighting some of the features of residential and vocational services for people with learning disabilities that are pertinent to studies on injuries, falls and accidents in this population. For example, the likelihood that some of the care/support staff in these services will be certificated first-aiders, and that a first aid kit at least will be in situ in both residential as well as vocational services (as residential settings will also be work places for care/support staff and subject to occupational health and safety regulations), and also that there will be formal (organisational) procedures for recording and reporting injury incidents within these services, which may vary across and within services.

The next three studies to follow (Wagemans et al., 2006; Hale et al., 2007; Chiba et al., 2009) were published after the data collection period for the research project contained within this thesis was completed.

Wagemans et al. (2006) published a report on their investigation into falls and fractures experienced by 338 adults with learning disabilities (aged < 20 years to > 80 years) residing at 'Maasveld' in the Netherlands over a 33-month study period. Maasveld is a campus-based residential setting of group homes for adults with learning disabilities. Falls were recorded by their nursing staff on a weekly basis, and personal and health information was also collected, including data on visual impairment (below 0.5 visual acuity), and hearing impairment (below 30 decibels loss of hearing function). The results demonstrated that 205 (61%) of the adults with learning disabilities had fallen at least once during the study period, of whom 97 (29%) had experienced three or more falls. Of the total number of 383 injurious falls reported, 26 (8%) had resulted in fracture/s. These authors identified the following factors as being significantly ($p < 0.05$) associated with both fall incidence (≥ 1 fall) and repeated falls (≥ 3 falls); epilepsy, antiepileptic drugs, fractures in the past, ambulatory, ageing, visual impairment, and hemiplegia. They found no significant association between falling and Down syndrome, diplegia, gender, hypotonia, orthopaedic problems, hearing impairment, psychopharmacological medications, and use of hypertensive drugs. (The actual p-values were not listed for any of these factors). These results are limited because of the restricted protective environment (campus-based) sampling, and the factors that were included in the analysis were only tested for their associations to falls.

Another study of 20 adults with profound learning disabilities who use residential and vocational services in New Zealand, 15 of whom were described as frequent fallers, assessed balance capabilities at a physiotherapy clinic, to identify possible reasons for falling. However, the sample size was too small to investigate the differing and complex combinations of potential risk factors for falls that each participant presented with, and the only commonality found between participants was their abnormal gait patterns. A number of the tests which are routinely carried out by physiotherapists to assess capabilities were also found to be unsuitable for use with the adults with profound learning disabilities, mainly because they were unable to understand what was required of them. The authors concluded that larger studies are required because the reasons why persons with learning disabilities fall appear complex and multi-factorial. Tests tailored more towards their use with people with learning disabilities is also suggested (Hale et al., 2007). In their review of how the strategies used to evaluate and prevent falls in the general population of older adults translate to use in adults with learning disabilities, and in light of e.g. the risk factors for fall/injuries identified by Hsieh et al. (2001), Brady et al. (2008) also concluded that risk factors, evaluation, effective interventions, and prevention strategies may differ for persons with learning disabilities.

In Japan, Chiba et al. (2009) investigated fall risk in 144 adults with learning disabilities who live in a large congregate care home. Data was collected from the participants' medical records and reports of fall incidents recorded by caregivers. Annual assessments of gait and balance in a sub-sample of 75 older adults with learning disabilities (aged 50 – 69 years) were also performed from 2003 to 2006 by a neurologist using the Tinetti assessment tool [Levine et al., 2001]. Of the 144 participants, 41 (28.5%) had experienced two or more falls in the preceding three months and were classified as fallers. Advancing age (OR 1.06), epilepsy (OR 6.55), and paretic conditions (OR 30.98) were found to be independent risk factors for falls. Paretic conditions refer to conditions with slight or partial paralysis, such as cerebral palsy. The Tinetti assessment tool was also found to be a valid and reliable tool for detecting fall risk in older/adults with learning disabilities. Like Hsieh et al.'s (2001) study, the main limitation of this study was the biased sampling, hence the findings are not generalisable. The independent risk factors for falls identified for this particular group were based on cross-sectional observation, which does not imply a causal relationship. The authors concluded that prospective studies are needed to test the validity of their results.

Two other studies investigated the incidence of non-fatal injuries in adults with disabilities (Xiang et al., 2005; Brophy et al., 2008). Their findings are not specific to adults with learning disabilities, thus not comparable. Brophy et al. (2008) utilised the 2004/2005 NHIS data set to investigate the incidence of at least one medically attended injury in adults with disabilities aged 18 years and over in the previous three months, compared with adults *without* disabilities in the general population. The 3-month cumulative incidence of injuries was 2.3% among adults with no disabilities; 3.8% among adults with moderate disabilities; and 5.6% among adults with severe disabilities. In this particular study, adults were categorised as having moderate disabilities if they (or someone in their household by proxy) answered yes to at least one of the following four questions:

- *Are you limited in any way in any activities because of physical, mental, or emotional problems?*
- *Are you limited in any way because of difficulty remembering or because you experience periods of confusion?*
- *Are you limited in the kind OR amount of work you can do because of a physical, mental or emotional problem?*
- *Because of a health problem, do you have difficulty walking without using any special equipment?*

Adults were categorised as having severe disabilities if they (or someone in their household by proxy) answered yes to at least one of the following two questions:

- *Because of a physical, mental, or emotional problem, do you need help of other adults with personal care needs, such as eating, bathing, dressing, or getting around inside the home?*
- *Because of a physical, mental, or emotional problem, do you need help of other adults with routine needs, such as everyday household chores, doing necessary business, shopping, or getting around for other purposes?*

In an earlier study on injuries experienced by a random sample of adults (aged 18 years and over) living in 2, 380 urban and 1, 926 rural households in Colorado, United States, Xiang et al. (2005) utilised the same moderate and severe categories from the same series of questions, although they had included a third question to categorise adults with severe disabilities (who answered yes to at least one of the three), which was *'Using special equipment or help, what is the farthest distance that you can go?'* (Participants who could not go farther than one or two city blocks were considered as having severe limitations). Xiang et al. (2005) found that 24% of adults with severe disability/limitations and 17.8%

of adults with moderate disability/limitations had been injured in the previous twelve months, compared with 12.6% of adults with no disability/limitations. It is clearly demonstrated by this series of questioning that these findings are pertinent to all adults with disabilities, including physical disabilities e.g. mobility problems and other limiting conditions such as mental health problems e.g. dementia, and results were not reported separately for adults with learning disabilities.

Six of these previous studies investigated injuries, accidents and falls in samples comprising adults with learning disabilities only (Hsieh et al., 2001: Grant et al., 2001; Donald Beasley Institute, 2001; Wagemans et al., 2006; Hale et al., 2007; Chiba et al., 2009). Four of these studies investigated risk factors for falls/fall injuries (Hsieh et al., 2001; Grant et al., 2001; Wagemans et al., 2006; Chiba et al., 2009), but only one of these investigated *predictive* risk factors, and this was within an institutional setting (Hsieh et al., 2001).

Of the twenty-two main risk factors identified for falls in older adults without learning disabilities in the general population (*table 1.1*) (World Health Organization, 2008a), three were reported as being either associated or predictive risk factors for falls/fall injuries in the literature on adults with learning disabilities who live in residential care settings; namely older age (Hsieh et al., 2001; Wagemans et al., 2006; Chiba et al., 2009), visual impairment (Wagemans et al., 2006), and antipsychotic/antiepileptic drugs (Hsieh et al., 2001; Wagemans et al., 2006). The other associated or predictive risk factors reported for adults with learning disabilities were not listed in the main risk factors identified for older adults in the general population; namely being ambulatory (Hsieh et al., 2001; Wagemans et al., 2006), epileptic seizures or epilepsy (Wagemans et al., 2006; Chiba et al., 2009), (Hsieh et al., 2001), destructive behaviours (Hsieh et al., 2001), co-morbidity (Grant et al., 2001), previous fractures (Wagemans et al., 2006), hemiplegia (Wagemans et al., 2006), and paretic conditions (Chiba et al., 2009). This is displayed in *table 1.3.*

Table 1.3. A Comparison of Risk Factors for Falls for Adults with Learning Disabilities and Older Adults in the General Population

I. Factors identified in the literature for both older adults in the general population, and adults with learning disabilities
Older age Visual impairment Polypharmacy / Antipsychotic/antiepileptic drugs
II. Factors identified just in the literature on adults with learning disabilities:
Level of learning disabilities Epilepsy Problem behaviours Hearing impairment Impaired mobility Hemiplegia Cerebral palsy Overly sociable temperament Previous fractures Co-morbid symptoms Frequency of epileptic seizures
III. Factors identified just in the literature on older adults in the general population:
Gender Socio-economic status Urinary incontinence Foot/toe deformity Body mass index Poor gait/balance Sedentary behaviour Fear of falling Poorly fitting shoes Ethnicity Diabetes Parkinson's disease Alcohol misuse Alzheimer's disease Depression Muscle weakness Stairs/steps Cognitive impairment Previous history of falls

A further important finding from this review of the literature with adults with learning disabilities, and with children with learning disabilities (reported in section 1.5) is that instruments and measures which are used routinely with people in the general population may not be suitable for use with adults with learning disabilities, because they are not tailored for them, and so require modification (Sherrard et al., 2004; Hale et al., 2007). To date, there have been no purpose-designed measures tailored for this population.

1.6.1. Risk of Injury Assessment

Konarski et al. (2005) made a recent attempt to assess the risk of injury in adults with learning disabilities living in an intermediate care facility. These American authors developed a brief instrument to assess risk of injury, which was applied retrospectively for two years (n=384) and prospectively for one year (n=355) to young persons and adults aged 14 to 81 years with learning disabilities, who were living in the same intermediate care facility. The risk of injury assessment comprised the sum of scores derived from points given to answers to eight questions. The questions cover the incidence of injury in a 12-month period, person's ability to walk, antipsychotic medication use, and the presence of a psychiatric diagnosis, the presence and effects of any problem behaviour/s, the presence of epilepsy, and health conditions, such as cardiovascular or respiratory. The actual questions that were included in the risk of injury assessment instrument are given in the appendix (*appendix 1*).

Results demonstrated that the percentage of young persons and adults with learning disabilities who experienced an injury significantly increased across the levels of increasing risk indicated by the assessment. Furthermore, the young/adults with learning disabilities with the highest risk scores had an injury rate of 78 per 100 people, which was more than three times the injury rate of 23.8 for the young/adults with learning disabilities who had the lowest scores. Inter-rater reliability (mean correlation 0.79) and test-retest reliability (mean correlation 0.90) on individual items, and correlations of 0.91 and 0.95 respectively on total score, demonstrate that the development of a reliable risk of injury assessment tool for use with persons with learning disabilities has promise. This particular tool however, only builds on the limited research in this area to date, including the previous work of Konarski et al. (1997), which reported that certain individuals living in intermediate care are especially prone to injuries, given that 16% of individuals accounted for two thirds of episodes of injury observed in a 12-month period. They could be differentiated from others by the fact they were more likely to be taking antipsychotic medications, had higher frequency of maladaptive behaviours, required more supports to

manage their maladaptive behaviours, and scored relatively highly on measures of self-care, communication, and motor skills. We do not know if this risk of injury assessment tool is suitable for more general use with non-institutionalised persons with learning disabilities.

1.6.2. Fracture Risk

People with learning disabilities appear to be at an increased risk of fractures, due both failure to build up bone density in their early years, and its depletion with a higher rate of osteoporosis. Many factors contribute to this, including the side effects of anticonvulsant medications on bone density (which are used in the treatment of epilepsy and in the management of problem behaviours), low Vitamin D levels due to a high proportion of time spent indoors, immobilisation (e.g. wheelchair users), and earlier onset of menopause thus osteoporosis risk for some women with specific types of learning disabilities (e.g. Down syndrome) (Angelopoulou, 1999; Lohiya et al., 1999; Schrager et al., 2007). Schrager et al (2007) reviewed the primary health care charts of 93 women with learning disabilities (aged 18 years and over) in the United States, and found than 30 (32%) had a history of adult-onset fracture/s. Due to incompleteness of the data collected however, these authors were unable to compare the fracture rate with women *without* learning disabilities in the general population. They also noted that many of the fractures described in the study were not typical of osteoporotic fractures, which raised the question of whether some of the fractures were due to an increased rate of clumsiness or instability, thus falls and other accidents, rather than osteoporosis.

Lohiya et al. (1999) reviewed the records of 994 people with learning disabilities (47 aged 17 years and under, and 947 aged 18 years and over) who lived in a residential centre in the United States, and found that 318 (32%) had a history of fracture/s. One hundred and fourteen (11.5%) of these residents had experienced at least one fracture during the preceding 3.5 years. The observed fracture rate was 1.7 times greater than the fracture rate for the United States general population. Of the total number of 182 (100%) fractures recorded, given that some participants experienced more than one fracture in the 3.5 year period, the cause was unknown in 105 (58%), with the remainder caused by falls in 41 (23%) (34, 19% of which were seizure-related), accidents other than falls in 15 (8%) (caught in a door 8, 4%; falling objects 7, 4%), self-injury in 11 (6%), harm (assault) from another person in 5 (3%), and care-related (e.g. transfers from bed to chair, therapeutic exercises) in 5 (3%). These authors found that the fracture rate was significantly greater in residents with epilepsy (odds ratio (OR) = 1.9), male gender (OR = 2.1), older age (odds

ratio not given), white race (OR = 3.3), osteoporosis (OR = 2.8), but significantly reduced in residents who were non-ambulatory (OR = 0.4), requiring high dependency skilled nursing care (OR = 0.4), and have profound learning disabilities (OR = 0.9).

These studies on fractures are of related interest but do not provide any direct evidence of the actual risk of injuries overall in the learning disabilities population. The studies by Lohiya et al. (1999) and Schrager et al. (2007) both demonstrate a high rate of fractures in 32% of people with learning disabilities, but due to the limitations of their restricted sampling (residential/nursing home residents in one sample, and only 93 women with learning disabilities in the other), the reasons for this have not been fully explored, particularly in relation to the fractures caused by falls and other accidents that were suggested. The study by Lohiya et al. (1999) in particular, is useful for highlighting some of the problems and concerns associated with the identification of fractures, thus injuries in people with learning disabilities; as the causes of 105 (58%) of fractures recorded were unknown. The records reviewed in this study for fractures were the result of routine monitoring of all residents for signs of injury (e.g. of pain, swelling, bruising, or refusal to use a part of their body), whereby all suspected injuries were evaluated by a physician and x-rayed. Routine monitoring was required because many of the residents with learning disabilities, due to the severity of their learning disabilities, were unable to identify an injury or verbalise its effects, and many fractures could not be diagnosed unless there was signs of pain, swelling, bruising, and so forth. That the majority of fractures recorded were only identified through routine monitoring clearly demonstrates the severity of the problem of fracture/injury identification in people with severe/profound learning disabilities, and places emphasis on the need for routine monitoring for fractures/injuries in this population, or at the very least that extra care and vigilance is required.

1.7. Carers Injuries

The term carer refers to either the person with learning disabilities' informal/unpaid family carer or formal/paid carer, depending on his/her supported/living arrangements. Carers of adults with learning disabilities play a crucial role in maintaining the health and well-being of persons with learning disabilities. The health and well-being of carers of persons with learning disabilities in turn therefore, is of equal importance, for the continuation of their caring/supportive role. The literature on this topic however, is somewhat limited.

Carers are a heterogeneous group. Primary unpaid carers of adults with learning disabilities who live with their family are typically their mothers, and are far less likely to be their spouse or child (due to fewer instances of adults with learning disabilities living with a spouse/partner or child-bearing) (McConkey, 2005). Many unpaid carers are elderly. Unpaid carers of adults with learning disabilities can also differ from other unpaid carers e.g. of adults with mental health problems, in that they recognise the need for the person's life-long care/support during the early years of life (Pruchno et al., 1996; Chou et al., 2009). For unpaid carers this can be a life-long commitment, and often involves 24-hour care/support.

In a national survey of 1, 449 family carers in Australia who were contactable via support organisations and service providers, Briggs and Fisher (2000) found that only 16% rated their health and well-being as excellent to good, and the 84% of carers who had a poor health rating attributed this to their caring work including the constant pressure of caring, disturbed sleep, and physical lifting. Physical injuries were highlighted as a major outcome of caring: nearly a third of all carers had been injured at least once in the course of caring. Strains, sprains and injury to muscles and joints represented 70% of direct injury to respondents as a result of their caring role. Back problems relating to manual handling such as lifting and lowering were identified by 30% of those with direct injuries. Re-occurrence of injury was common. The estimated annual injury rate for family carers was 5%. These results however, do not include family carers who were not in contact/receiving support from at least one of the support organisations and service providers.

In their study of 46 unpaid carers of elderly patients with disabilities admitted under a hospital respite scheme, Brown et al. (1997) found that of the 41 (87.2%) unpaid carers who participated, 31 (75.6%) had injured themselves during lifting and handling, and 16 (39.1%) of the persons they cared for had been inadvertently injured whilst being lifted and handled by their carer. Of the 31 carers who had injured themselves, 18 (58.1%) had received no training/instruction on safe lifting and handling techniques. Most of the carers in this particular study were elderly (over 70 years of age) and 21 (51.2% of those who participated) had a medical condition which restricted their own physical activity. The small scale and restricted sampling of this study limits the conclusions that can be drawn, but it is still useful for demonstrating the day-to-day difficulties of care-giving, which can result in injury to self and others.

Research on the health and well-being of carers of adults with learning disabilities has tended to focus on the impact of their role on their development of health conditions and/or psychological well-being, rather than injuries. A study of 982 family carers of adults with learning disabilities living in Leicestershire for example, found that carers reported 40% more limiting health conditions compared to the general population, with depression almost four times more common amongst female carers (McGrother et al., 2007).

1.7.1. Caring for Persons with Learning Disabilities with Problem Behaviour/s

Stress and risk of injury in relation to caring for a person with learning disabilities and problem behaviours e.g. physical aggression has also been the subject of study amongst carers (Harris, 2008; Tyrer et al., 2006). In their secondary analyses of population-based data available for 1, 362 children and adults with learning disabilities in a single South Western health district of the United Kingdom for example, Harris (2008) found that 17.6% (240 persons) had aggressive behaviour, but the risk of serious injury to another person was very low; 0.7% (6 persons) were reported to be presenting such a risk to others. In their cross-sectional analyses of interview data collected from 3, 065 adults with learning disabilities (and their carers by proxy) in a geographical region in England, United Kingdom, Tryer et al. (2005) found that 14% (443) of the adults with learning disabilities were reported by their carers to be physically aggressive towards others. Men ($p = 0.001$), younger individuals ($p < 0.001$), people with more severe learning disabilities ($p < 0.001$), and those in institutional settings ($p < 0.001$) had a significantly higher prevalence of physical aggression, but people with Down syndrome had a significantly lower prevalence ($p < 0.001$) of physical aggression. Forty-two per cent of carers of adults with learning disabilities with aggression reported that they felt unable to cope, compared with 10% of carers of carers of adults with learning disabilities *without* aggressive behaviour.

Persons with learning disabilities who have aggressive behaviour are more likely to require assistance or support with their personal and daily living activities, so require more care (Emerson et al., 2001). These are common disorders: a recent population-based study of adults with learning disabilities, based of clinical mental ill-health screening and assessment, reported point prevalence for physically aggressive behaviours towards others of 9.8% (Cooper et al., 2009).

1.7.2. Fatal and Non-Fatal Injury

One study by Hill-Smith and Hollins (2002) has examined the causes of death of parents of persons with learning disabilities and reported that 3.5% of mothers and 2.3% of fathers had died as a result of accidents, including violence. This compared with 2.6% of women and 4.0% of men in the general population.

To date, no study has examined non-fatal injuries specifically experienced by carers of adults with learning disabilities who are representative of the whole population with learning disabilities, although, as the review of this literature demonstrates, there are a number of reasons why investigation of this is warranted; from the burden of caring generally (e.g. injuries related to manual handling), to the risk of injury living/working with persons with learning disabilities who have problem (or challenging) behaviour/s.

1.8. Conclusions from Review of the Literature

Whether the higher reported injury rate for children with learning disabilities is also experienced by adults with learning disabilities has not yet been the subject of rigorous study and it is an under-researched area. There is, however, a suggestive trend in the existing literature. There are also theoretical reasons to anticipate that a higher rate of injury does indeed exist, in view of the population's high rates of physical and mental ill-health, including factors, which have been identified as risk factors for falls among the older general population, and epilepsy, which has also been found to be associated with risk. These factors include diabetes (Sohler et al., 2009), depression (Cooper et al., 2007; Kwok and Cheung, 2007), incontinence (Chapman et al., 2008), dementia (Zigman et al., 2004; Holland et al., 2000; Cooper et al., 1997a), poor gait/balance (Carmeli et al., 2003), muscle weakness (Howells, 1986), sensory impairment (Owens et al., 2006; Reichman and Healey, 1983), foot problems (Howells, 1986), being underweight (Emerson, 2005), sedentary behaviour (Finlayson et al., 2009), polypharmacy/antipsychotic drugs (Santosh et al., 1999), and ill-fitting shoes (Jenkins et al., 2011). This has important public health implications, and highlights the need for bridging this research gap, to gain a greater understanding of the prevalence of injuries and accidents, and their causes, from which appropriate preventative strategies could then be developed.

Summary

This chapter has introduced the phenomena of injuries, falls and accidents within the general population/population of older adults, and in doing so, has drawn special attention to the issues related to this particular area of study e.g. the definition/s and meanings attached to the term 'fall'. Important consideration of these methodological issues was necessary for conducting the research project which is contained in this thesis, which will be demonstrated in the chapter on Methods.

This chapter has synthesised the literature on injuries, accidents and falls that is specifically relevant for adults with learning disabilities. The research gap identified from the review of the limited literature available on the frequency and types of injuries, falls and accidents experienced by adults with learning disabilities, and what little we know of the factors associated with them, formed the basis of this research project, which has attempted to address this gap. The few papers addressing injuries experienced by carers of people with learning disabilities were then reviewed. The specific research aims and research questions of this research project are derived from what is, and is not yet known from the existing literature, and are presented in the next chapter.

CHAPTER 2:
RESEARCH AIMS AND QUESTIONS

2.1. Research Aims

The aims of this research are:

1. To determine the incidence and types and causes of injuries experienced by a community-based cohort of adults with learning disabilities.
2. To compare these findings with the general population in the same geographical region.
3. To identify risk factors for injuries, accidents and falls.

These are steps 1 and 2 of the four key-step injury prevention approach previously described in section 1.2. These steps are necessary as a first stage towards informing the next-step, which would be the design and evaluation of tailored interventions on a broad scale. A further aim is:

4. To determine whether carers of adults with learning disabilities are more prone to injuries when compared with i) the adults with learning disabilities they support, and ii) the general population in the same geographical region.

2.2. Research Questions

The specific research questions that this study will answer are as follows:

1. What is the incidence of unintentional and intentional injuries and falls in adults with learning disabilities over a 12-month period?
2. What are the types and causes of unintentional and intentional injuries and falls experienced by adults with learning disabilities over a 12-month period?
3. Are adults with learning disabilities more prone to injuries, accidents and falls, when compared with published general population data?
4. Can demographic, lifestyle, health and disabilities factors be identified as risk factors for injuries, accidents and falls of adults with learning disabilities?
5. What factors are perceived by adults with learning disabilities and their carers as contributing to injuries, accidents, and falls of adults with learning disabilities?
6. To what extent are aids and adaptations, risk assessments, and incident reporting utilised?
7. Are carers of adults with learning disabilities more prone to injuries, accidents and falls when compared with a) the adults with learning disabilities they support and b) published general population data?

CHAPTER 3:
METHOD

Overview

The research project contained within this thesis was 'built on' to a larger quantitative research study, which was longitudinal in design, at time 2. Time 1 (T1) in the larger study refers to the first point in time for data collection at baseline, and time 2 (T2) refers to the second point in time for data collection, during a two-year follow up period.

In this chapter, this research project on 'injuries, accidents and falls in adults with learning disabilities', and the author's role, is first described in relation to the wider programme of research it was built on to. This provides the reader with context, and sets out the distinctiveness of this research project as a separate unique study. The second part of this chapter then considers methodological issues, particularly those around conducting research with adults with learning disabilities, and details the methods that were employed to conduct this research project.

3.1. Research Environment and Context in Relation to the Larger Research Study

The larger longitudinal research study was conducted over the years 2002 and 2006, and involved data collection at two different points in time, at baseline (T1) during the years 2002 to 2004, and at two-year follow up (T2) during the years 2004 to 2006. The larger research study was conducted as part of the University of Glasgow's Centre for Excellence in Developmental Disabilities (Glasgow UCEDD) research programme, led by Professor Sally-Ann Cooper, which was aimed at improving the health and well-being of persons with learning disabilities. The author was employed as a Research Assistant on projects related to the larger research study during the time 1 phase of data collection (Finlayson et al., 2004; Melville et al., 2005; Melville et al., 2006; Cooper et al., 2006; Romeo et al., 2009).

The larger research study at time 1 was a health check intervention study, whereby a Primary Care Liaison Team (PCLT) of learning disabilities research nurses was set up to offer and carry out free health checks to the community-based population of adults with learning disabilities (aged 16 years and over) who live in the Greater Glasgow area (Cooper et al., 2007). These health checks involved a review of each participant's primary care medical and psychology/psychiatry records, followed by a home visit research interview, a physical examination and blood tests. Data collected during these health checks is detailed in the relevant sections to follow.

The larger research study at time 2 was more specifically aimed at determining the incidence and predictors of mental ill-health in this population-based cohort of adults with learning disabilities (Smiley et al., 2007), and as such, involved a home visit research interview with each participant, and referral to a learning disabilities psychiatrist for some participants (those who possibly or probably had psychiatric disorders, autism or problem behaviours). Psychology and psychiatry records were reviewed, and secondary care medical records for those who had the psychiatric assessment, and there was no routine physical examination. Again, data collected during this two-year follow up study is detailed in the relevant sections to follow.

The home visit research interviews at time 2 were conducted by two research assistants (researchers), one of whom was the author. The author's employment on this two-year follow up study provided an opportunity for her to enrol as a PhD student at the University of Glasgow, and additionally conduct her own research project within a supportive research environment, as part of this wider research programme aimed at improving the health and well-being of persons with learning disabilities. The author's research project being built on to the larger research study at time 2 enabled her to utilise both the large population-based sample of adults with learning disabilities during the same 2004 to 2006 period, and both T1 and T2 data for her own investigation into the incidence and predictors of injuries, falls and other accidents experienced by adults with learning disabilities. Due to the existing length (duration) of these home visit research interviews however, the amount of time available to collect data on this topic was limited. The author could not introduce too many additional or lengthy measures, or any measures involving a physical assessment/examination which were not in keeping with the other larger study's T2 data collection instruments. A home visit research interview during the T2 phase of data collection typically took an estimated one hour and forty minutes to complete, although the actual time taken did vary from individual participant to individual participant.

As per the T1 health check study, a secretary was also employed full-time for the duration of the T2 two-year follow up study. Her duties included posting the invitation letters to participate in the study to potential participants (which the researchers followed up with telephone calls, in keeping with the ethically approved protocol), answering the telephones when the researchers were not available (to ensure potential participants were able to speak to a person about the study, and not have to leave a message on an answer phone), and to ensure the researchers' safety during their home visits. This involved the secretary

managing each researcher's appointments diary, and each researcher telephoning the secretary to 'call in' to the office within an hour of completing each home visit research interview (based on an estimated 1 hour and 30 minutes interview). A researcher's failure to report back to the office on completion of a home-based research interview would have resulted in the principal investigator being notified, if it had happened.

The larger research study at time 1 was funded by the Greater Glasgow and Clyde Health Board and the West of Scotland Research and Development Mental Health Programme. At time 2, the research study was funded by the Chief Scientist Office (CSO), Scottish Government Health Department. Both studies were approved by the appropriate Research Ethics Committee, as described in section 3.3 'Ethical Approval and Consent' of this thesis.

3.1.1. Identification of Potential Participants

The population of adults with learning disabilities (aged 16 years and over) residing in Greater Glasgow had been ascertained prior to commencement of the larger health check study (Cooper et al, 2007). The population ascertainment rate was 3.33 per 1, 000 general population; which is in keeping with other large-scale population ascertainment (Farmer et al, 1993; McGrother et al, 2001; van Schrojenstein Lantman de-Valk et al, 2006). The process identified all adults with learning disabilities who were registered with a general practitioner in Greater Glasgow (all 631 general practitioners contributed to the ascertainment process), adults with learning disabilities who were receiving support of any type paid for, or provided by, the social work department, including day services and support packages of any size, and adults with learning disabilities who were using specialist learning disabilities services or had done so in the past. The general practitioners were incentivised to identify adults with learning disabilities who were registered with them, as the Health Board established an additional annual capitation payment to be provided to general practitioners for each person with learning disabilities on their list, in view of the associated individual workload. All of the identified adults with learning disabilities were invited to participate in a programme of research, with no exclusions. Subsequent exclusions were adults who, at the assessment, were found not to meet the criteria for learning disabilities, or whose postcode had been incorrect, and were actually living outside of the strictly defined geographical boundaries of the study.

3.1.2. Baseline (T1) Participants and Process

Comprehensive health checks/assessments were conducted by six PCLT research nurses, with each discussed with one of three general practitioners. They were completed on 1, 023 adults with learning disabilities between the years 2002 and 2004. This was 65.5% of invitees (Cooper et al, 2007). Participants were supported by their carers (support workers or relatives) during these face-to-face assessments. Interviews were also conducted with a relative, for whom the main carer was not a relative. These assessments provided baseline (T1) data on all participants, which included physical and mental health, developmental, and demographic information.

Data was collected on personal characteristics, physical and mental ill-health and disabilities, lifestyle and supports. Physical examinations were also conducted, including vision and hearing assessments. Adults identified to have possible or probable mental ill-health, problem behaviours or autism had a further comprehensive psychiatric assessment by a consultant psychiatrist who specialises in learning disabilities psychiatry to derive diagnoses. Medical and psychology/psychiatric cases records were reviewed for all participants, including primary health care records, which also contained details from secondary health care appointments and admissions.

3.1.2.1. T1 Materials

The instruments that were used for data collection at T1 are described as follows.

1. A purpose-designed semi-structured demography questionnaire.

This included data on age, gender, occupation, type of accommodation/support, and postcode. Postcode was used to derive Carstairs deprivation quintiles, which was the most commonly used area-based measure of deprivation in Scotland at the time (Carstairs et al., 1989).

The Carstairs index is based on four census indicators; low social class, lack of car ownership, overcrowding and male unemployment. These four variables are measured against the Scottish average and re-scaled so that they have the same degree of variation across Scotland. The resulting transformed variables (z – scores) are given equal weight and combined to form an overall index of deprivation by postcode. The Carstairs deprivation index quintiles range from 1 (most deprived) to 5 (least deprived) (Scottish Executive, 2003).

2. The C21st Health Check.

The C21st Health Check (Glasgow U.C.E.D.D., 2001) collects information on physical and mental ill-health, problem behaviours and disabilities through review of medical and nursing primary health care records, face-to-face assessment, and physical examination, including examination of visual acuity and hearing, and assessment of communication skills, and blood tests. The C21st Health Check is a modification of the Comprehensive Health Assessment Program, an Australian health check for people with learning disabilities designed by Professor Lennox and colleagues (Lennox et al., 1999). Approval was given by Professor Lennox to modify it.

Kay's pictures (Kay, 1984) were used in the C21st Health Check to assess visual acuity because they are used in routine clinical practice with this population, as standard Snellen charts cannot be used with many people with learning disabilities, as they do not know the alphabet. The protocol for visual assessment was provided by clinical academics at Glasgow Caledonian University Visual Sciences Department (who also run a specialist visual assessment service for persons with learning disabilities). They also trained the research nurses in its use, and conducted the detailed visual assessments on the people whom the nurses found to have possible visual impairments following the vision screen. The visual screen protocol is included in the C21st Health Check. It first requires a series of 9 questions to be asked to help detect any possible problems (e.g. for persons unable to self-report, carers were asked whether the person screws up his/her eyes when in bright sunlight), then measuring vision using Kay's pictures at 33 centimetres and 3 metres, and referring persons with possible visual impairment to the Glasgow Caledonian University Visual Sciences Department for more detailed, specialist assessment. In this study, persons with refractive errors not corrected by spectacles (e.g. because the person wouldn't wear them) were also included in the category of having visual impairment, but persons with a refractive error that was appropriately corrected by spectacles were not.

Hearing, likewise, was assessed through a series of questions, then otoscopy, and if the tympanic membrane could be visualised, examination using Warblers at 1/2m at the level of 30db/500Hz, 30db/1000Hz, 30db/2000Hz, and 30db/4000Hz, with referral for specialist assessment if there was any suggestion of possible hearing impairment. If the tympanic membrane could not be visualised because of impacted cerumen, drops were first used, to clear it. In the analyses, persons were not included as having hearing impairment if it was fully corrected with hearing aids, but they were included if hearing remained impaired despite the use of aids, or if the person would not wear aids.

Mobility was assessed through discussion with the person and their relative/support worker, to determine whether the person was fully mobile, walks with stick/s, frame or assistance, required a wheelchair outside only, required a wheelchair in and outside, could weight-bear to transfer only, or could not weight-bear. In the subsequent analyses, this was dichotomised to whether or not the person was fully mobile.

The protocols that are included in the C21st Health Check and phlebotomy were based on published clinical guidelines where they existed, or accepted best practice where there are none. The diverse range of clinical health needs that the C21st Health Check can identify does not easily apply itself to psychometric study, and the tool is only suitable for use by qualified health professionals trained in clinical decision-making. It has however, been the subject of some study, using qualitative and quantitative research methods. As a precursor to this larger study, the C21st Health Check was developed and studied in a project with 50 adults with learning disabilities (Curtis et al., 2001). The information was collected by qualified nurses, who received additional training in e.g. visual assessments, hearing assessments, and phlebotomy. The clinical information they collected from scrutiny of each person's general practise (primary health care) case notes, the interviews and examinations with the participants and their carers was case-conferenced by the research team which included principal general practitioners (GPs), consultant psychiatrists and nurses in learning disabilities, and classified using the ICD-10.

The qualitative study with these 50 participants used the framework approach to investigate the perceptions of people with learning disabilities on their experience of the health check, and those of their carers, with detailed individual semi-structured interviews. Focus groups were also conducted with the nurses to seek their views on the health check. From this, it was concluded that the instrument had good utility, and hence its use in the baseline measures for this larger study. At baseline data collection for this larger study, results from the health checks were also passed to the persons own general practitioner (GP) for use in their subsequent NHS treatment. Information was subsequently sought from the GPs regarding the health check information, and provided by 385 of the 631 GPs (61%): 94.1% reported the information to be useful and accurate (3.9% did not find it so, and 2.0% were unsure), and 73% reported it was better information on their patients' health needs than they had from previous alternative sources, whilst 23% were not sure, and 4% thought not. Important health needs were identified by the health check which may not otherwise have come to the attention of the GP for some time or indeed ever,

according to 35% of GPs. This is the baseline health information that is used in this subsequent PhD.

3. Mental ill-health screening and assessment.

A two-stage procedure was used to collect data on mental ill-health at baseline; screening, followed by detailed psychiatric assessment. A Psychiatric Assessment Schedule for Adults with Developmental Disabilities (PAS-ADD) Checklist (Moss et al, 1998) was completed for everyone. This is a screening tool for mental ill-health designed for use with adults with learning disabilities; it is not a diagnostic tool. However, when using the published threshold scores (which are a score ≥ 6 for the affective or neurotic disorder subscale, ≥ 5 for the possible organic condition subscale, and ≥ 2 for the psychotic disorder scale) the reported sensitivity of the tool is only about 66% (Moss et al, 1998; Simpson, 1999; Sturmey et al, 2005). Simpson's detailed study of the psychometric properties of the tool included receiver operating characteristic analyses for various possible ways of completing the PAS-ADD Checklist. These were completing the tool with (a) the person's main carer, (b) with two carers, and (c) with day centre staff, for each of scoring the scale by counting items using (a) the Likert scale, (b) any positive item, and (c) a mid-point threshold for each item (i.e. a score of 2 or 3). This found that when the PAS-ADD Checklist was completed with the person's main carer and a threshold of any two positive items was used, the tool had a 100% sensitivity to detect persons meeting criteria for an ICD-10 diagnoses with a false positive rate of 58%, and 95% sensitivity to detect persons meeting criteria for a DSM-IV diagnoses with a false positive rate of 53%. DSM-IV refers to the Diagnostic and Statistical Manual of Mental disorders – Fourth Edition (American Psychiatric Association, 1994). As would be expected, both sensitivity and false positive rate progressively reduced, the higher the threshold score (Simpson, 1999). The plan was to maximise the detection of true positives, at the cost of false positives at this first stage of the process, as the two stage process would mean that any false positives at stage 1 would be detected at stage 2 (the comprehensive psychiatric examination). Consequently the threshold of any 2 positive items across the whole scale was used, to trigger the second stage full psychiatric assessment. Additionally, a threshold of needing only 1 positive item was used if it was attempted suicide or talk of suicide, or any of the four psychosis items. Six new items were also added after the pilot study with 50 persons. These were aimed at detecting mania, and strengthening the psychosis subscale; and were specifically (a) lability of mood, (b) loss of social inhibitions/onset of inappropriate social behaviour, (c) increased interest in sex/sexual indiscretions, (d) excessive talking, laughing or singing, (e) tearfulness, (f) thinking that people or the television are referring to the person or giving

messages or instructions. In the pilot study with 50 people, the changes were investigated to increase case detection when used at the first stage of the two stage process, and found they did indeed lead to the identification of true cases who would not have been detected using the standard PAS-ADD Checklist thresholds.

A newer version of the PAS-ADD Checklist is now available [PAS-ADD UK, 2010]. However, the original version of the PAS-ADD Checklist was subject to detailed investigation, which the newer version has not been, as far as the author of this PhD thesis is aware, including the author's PhD supervisor having corresponded specifically on this point with the PAS-ADD Checklist author. The newer version contains fewer items than the original, and it is unclear whether, and to what extent, this reduces detection rate.

At the second stage to detect mental ill-health, a detailed psychiatric assessment was completed, to generate gold standard psychiatric diagnoses. Gold standard refers to a diagnostic or benchmark test that is regarded as definitive, a best practise methodology. This included completing the Present Psychiatric State for Adults with Learning Disabilities (PPS-LD) (Cooper et al., 1997b) with each person with learning disabilities and their carers, in addition to following a standard psychiatric assessment process over as many appointments as necessary, with information from the interviews, examinations, and case records being integrated. The PPS-LD is not a tool which provides a score; it is a clinical measure that contributes to gathering the clinical information across a full range of psychopathology, so that psychiatric diagnoses can be generated by whichever classificatory system is being used. It contains the psychopathology required to generate the main diagnoses in the Diagnostic Criteria for Psychiatric Disorders for Adults with Learning Disabilities (DC-LD) (Royal College of Psychiatrists, 2001), and the ICD-10 Diagnostic Criteria for Research (ICD-10-DCR) (World Health Organization, 1993), and DSM-IV-TR (Text Revision) (American Psychiatric Association, 2000), and also has additional items of relevance to the population with learning disabilities which can be used to contribute towards a clinical diagnoses (e.g. tearfulness). There is no other comparable instrument for use with the population with learning disabilities that the author of this PhD thesis is aware of, given that a previous instrument, the full version of the PAS-ADD, is not now in print, and indeed does not include a wide enough range of psychopathology to make some of the diagnoses in DC-LD and in DSM-IV-TR. In all cases the psychiatric assessments were completed by qualified learning disabilities psychiatrists, and all information case-conferenced by the consultant psychiatrist members of the research team to derive diagnoses at baseline. The assessments were therefore more comprehensive than

just using the PPS-LD, although this tool has been shown to have good psychometric properties. A study by Fitzgerald and Cooper, 1998 (both trained learning disabilities psychiatrists) recruited 37 adults with intellectual disabilities receiving in-patient management. Their mean age was 42.8 (22-75), and abilities ranged from mild to profound intellectual disabilities. Inter-rater reliability was good with Kappa scores in the very good range (0.81-1.0) in 82%, good (0.61-0.8) in 15%, moderate (0.41-0.6) in 1.5% and fair (0.21-0.4) in 1.5%. No items were in the poor range. Mean kappa across all items was 0.91 for intra-rater reliability and 0.88 for inter-rater reliability. Validity showed diagnostic agreement with that of the person's own consultant psychiatrist in 80.6%, with most differences being diagnoses that are closely associated (e.g. depressive episode versus mixed affective disorder) (Fitzgerald, 1998).

The PAS-ADD Checklist was also used to collect information on potentially traumatic life events any persons had experienced in the previous twelve months (e.g. death of a partner or parent, or moving home), using the 'Life Events' component of the Checklist. Additionally, instruments containing items to detect the psychopathology within autistic spectrum disorders and hyperkinetic disorders were purpose-designed for use by trained clinicians, within the context of a full psychiatric assessment. These were also used at the comprehensive psychiatric assessment.

3.1.3. T2 Participants and Process

The adults with learning disabilities (n = 1, 023) who were recruited into a longitudinal cohort at the first point in time (T1), between the years 2002 and 2004, were re-contacted and re-interviewed by research assistants at the second point in time (T2), two years later between the years 2004 and 2006. This was the incidence and predictors of mental ill-health in adults with learning disabilities study. The following instruments were repeated at time 2: a purpose designed semi-structured demography questionnaire; selections from the C21st Health Check, namely items on problem behaviours, epilepsy, and mental ill-health; and the original version of the PAS-ADD Checklist screening tool for the identification of possible psychiatric disorders in adults with learning disabilities. The Vineland Scale (Survey Form) (Sparrow et al., 1984) was also used to measure ability and skills, as well as a purpose-designed questionnaire to collect data on each person's personal history (e.g. father's occupation and place of birth). Once again, and particularly with regards to personal history data collection, interviews were also conducted with a relative, for whom the main carer was not a relative.

Psychiatrist assessment followed the same comprehensive assessment format as that for time 1. Psychology/psychiatric records were reviewed, and secondary care medical records for the persons who had a psychiatric assessment. Each person's feet were measured using a standard foot measuring stick, to determine whether or not they were wearing the correct shoe size when compared with their current footwear, but no other physical examinations were conducted.

The research project for this PhD was built on to this larger two-year follow up study.

3.2. Methodology

The research project for this PhD employed quantitative research methods to investigate the incidence, types, causes and characteristics of injuries, falls and other accidents experienced by a population and community-based cohort of adults with learning disabilities. It is an observational study, and it conforms to the STROBE guidelines, which outline recognised best research practice for observational studies. A questionnaire administered via face-to-face interviews was designed for this purpose. The questions that were included in this questionnaire were informed by the literature, and designed to be able to answer all of the research questions of this PhD project. The questions were designed to be directly comparable with published general population data for the same (Scottish Executive, 2005), as well as encompassing the likely types, causes and characteristics of injuries, falls and other accidents that are specifically experienced by adults with learning disabilities (e.g. paying particular attention to seizure-related falls, due to the much higher incidence of epilepsy in people with learning disabilities). Question design is of key importance in study design (Busha et al., 1980).

This PhD research project was built on to a larger study, as described. This was both beneficial to the research project e.g. in accessing a large longitudinal cohort of adults with learning disabilities, and restrictive (pre-defined), in terms of the timescale, and the types and number of measures the author was able to employ for data collection. The participants were only asked about injuries, falls and accidents at time 2 (cross-sectional rather than longitudinal), but the author was able to utilise time 1 data from the larger study at baseline, to investigate predictive risk factors for injuries, falls and other accidents in a longitudinal cohort.

3.2.1. Author's Role

The research project for this PhD was designed within a larger programme of work of longitudinal investigation of this cohort, which has just been described. This research project on the incidence and predictors of falls, injuries and other accidents experienced by adults with learning disabilities was designed by Janet Finlayson (author), with the guidance of her PhD supervisor, Professor Sally-Ann Cooper and her PhD Advisor, Professor Jillian Morrison. Janet Finlayson gained external research grant funding with her supervisors to implement this study. She reviewed the published literature on injuries, accidents and falls, and accessed the general population data. She designed and piloted the injury, accidents and falls data collection tool, and trained the two other researchers in its use. She collected 53% of the all the quantitative data at T2, two years after the first baseline wave (T1) of data collection. Two researchers, including Janet Finlayson, were originally employed on the T2 study full-time, but a third researcher was introduced in the last two months of the study, to replace the second researcher who had left to commence a new position in another university. Janet Finlayson coordinated the data collection for this project, conducted all of the data coding and data entry, and all of the analyses and their interpretation.

3.2.2. Conducting Research with People with Learning Disabilities and Their Carers

Conducting research with people with learning disabilities often involves their carers being present. A person because of his/her learning disabilities can experience difficulties with regards to making an informed choice to consent to participate, and subsequently participate in, research, such as lack of comprehension or acquiescence (Finlay et al., 2000). A person with learning disabilities' carer can support him/her during the research process, because the carer knows the person well and can assist with e.g. communication aids to understanding (Lewis et al., 2004), and/or answer any questions that he/she is unable to on his/her behalf, by proxy. Proxy consent by a person's nearest relative (or welfare guardian) is a recognised feature of learning disabilities research, particularly in the United Kingdom, which is based on the 'best interest' principle; whereby the proxy decides a person will participate in research on the basis that it will benefit the person and thereby be in his/her best interest (Wong et al., 1999; Iacano et al., 2003). Proxy consent is described more fully in the next section on 'Ethical Approval and Consent'.

Research involving adults with learning disabilities however, should always endeavour to include the person with learning disabilities as much as possible throughout the process, and encourage him/her to participate as much as he/she is able and willing to. Good

practise guidelines for researchers in this respect, which the methods of this thesis follows include:

- Providing more time for people with learning disabilities to make decisions about research and to be able to participate;
- Possessing skills for communicating with people with learning disabilities, and being able to tailor communication to the individual e.g. using shorter, simpler sentences, or using communication aids such as sign language, pictures/symbols/objects, or gestures (Cambridge et al., 2003);
- Ability to develop a rapport with persons with learning disabilities and their carers;
- Awareness of both the carer's and the person with learning disabilities' relationships to the research, ensuring for example, that the person with learning disabilities' willingness (or unwillingness) to take part is considered and respected (or acted on) at all times;
- Awareness of positive and negative non-verbal indicators e.g. eye contact, body language, nodding or shaking head, appearing restless, impatient, or distracted, and facial expression;
- Awareness of the problem of acquiescence and ability to for example, ask the question in different ways to check the person's comprehension; and
- Disseminating results of the research to participants in accessible information formats e.g. using pictures or symbols, or providing results on audiocassette or DVD ((Lewis et al., 2004; Cameron et al., 2006).

3.3. Ethical Approval and Consent

This PhD research project was approved locally by the Greater Glasgow Primary Care National Health Service (NHS) Research and Development Directorate, and nationally by the Multi-Centre Research Ethics Committee – Scotland A. The latter is a legal requirement, of Part five of the Adults with Incapacity (Scotland) 2000 Act (Scottish Parliament, 2000), for conducting research with adults who do not have capacity to consent. The Act safeguards the welfare (and finances) of people who lack capacity, and protects adults (aged 16 years and over) who lack capacity to take some or all decisions for themselves because of a mental disorder or an inability to communicate. It allows a person, such as a relative or welfare guardian, to make decisions on someone's behalf. A welfare guardian refers to someone, such as a person's relative or social worker, who is recognised by law to have power of attorney, which means authorisation to act on a person's behalf.

Part five of the Act states that research on adults incapable of consenting is authorised provided that a number of circumstances and conditions have been met or applied. Each of these circumstances/conditions is summarised as follows, in relation to how it was met or applied to conduct the research project for this PhD.

1. It will further knowledge:

The involvement of adults with learning disabilities who do not have capacity to consent in this research project was permitted, on the basis that the purpose of the research was to gain (or increase) our knowledge of the types, causes and characteristics of injuries, falls and other accidents experienced by adults with learning disabilities. People with learning disabilities are known to have different patterns of health when compared with adults *without* learning disabilities in the general population. Our understanding of injuries, falls and other accidents experienced by community/population-based adults with learning disabilities could not be increased if adults with learning disabilities across all levels of learning disabilities were not included.

2. It is of benefit to the adult or others in a similar condition:

The Act sets out that the research must be of direct benefit to the adult with learning disabilities involved, or where there is no direct benefit, that the research may be carried out if it is likely to improve the scientific understanding of the adult's condition (learning disabilities) and in the long-term contribute to the attainment of real and direct benefits to other adults with learning disabilities. This research was permitted on the understanding that it would build on and inform our understanding of injuries, falls and other accidents in adults with learning disabilities, and future strategies and interventions to minimise or prevent them in this population.

3. It entails little or no risk or discomfort:

Another requirement of the Act was that the adult's participation in the research would entail little or no risk or discomfort. The Act encompasses surgical, medical, nursing, dental or psychological research. It was not envisaged that that the adults with learning disabilities would experience any risk or discomfort through their inclusion in this PhD research project. Participants and their relatives/support workers were advised via the information sheets however, that if they felt unhappy in any way at anytime during the research (e.g. about the way they were being treated), then they had a right to, and should complain to, the NHS Greater Glasgow Primary Care Division. (No participants or their

carers complained about their treatment/participation in this research at any time, to either the research team or the local NHS Primary Care Division or any other body/organisation).

4. The adult is not objecting:

The Act states that the research must not be carried out if the adult indicates unwillingness. This was reiterated to the participants and their support workers/relatives in the information sheets, which clearly stated that they were in no way obliged to take part in this research project (there were no consequences if they decided not to), and that even if they did participate they were free to withdraw at any time without having to give a reason why.

The researchers responsible for conducting the research interviews for this PhD research project strictly adhered to this important requirement/condition at all times. Adults with learning disabilities who did not have capacity to consent were still involved (included) in the research interview as much as they were able to, and encouraged to answer any of the questions that they were able to on their own. If at any time during the interview the adult with learning disabilities gave any indication at all that he/she was unwilling to participate (e.g. through his/her non-verbal as well as verbal communication), the research interview was terminated. The adult with learning disabilities wishes (choice) were respected at all times.

5. Consent has been obtained from a person with relevant powers:

The Act sets out that before any research involving the adult is undertaken consent must be obtained from a welfare guardian; or the adult's nearest relative if no welfare guardian has been appointed.

In this PhD research project, consent was taken from each participant with learning disabilities who did have capacity to decide. Participants were provided with information sheets about the research project in advance, to help them decide whether or not they wished to take part, and the same information was available for them on audiocassette, if they preferred. Participants were encouraged to speak to others about the research project (i.e. their carers), to help them decide. Information sheets for relatives/support workers were also provided. Copies of the consent forms and information sheets that were used for this research project are included in the appendix: Participant Information Sheet; Support Worker Information Sheet; Relative Information Sheet; Relative Consent Form; Participant Consent Form; and Researcher Project Consent Statement Form (*appendices 2 – 7*).

For the participants with learning disabilities who did not have capacity to decide, approval (consent) for their inclusion in the research was sought from each person's welfare guardian or nearest relative. For the participants with learning disabilities who did not have capacity to decide who lived with paid support or in congregate care (out with the family home), their welfare guardian or nearest relative was contacted first, their questions answered, and their approval sought. The views of the person with learning disabilities, as far as they had the ability to formulate them, were still sought and respected, and all their questions were answered.

The actual numbers (percentages) of adults with learning disabilities who were included in this PhD research project who did or did not have capacity to consent, are reported at the beginning of the next chapter on 'Results'.

3.3.1. Confidentiality, Anonymity and Data Protection

The confidentiality of participants was respected at all times. Hard copies of the data collected were kept in a locked filing cabinet within a locked room in the Section of Psychological Medicine, University of Glasgow. Data entered onto a computer was made anonymous using a unique research number for each participant. The electronic data was kept securely. Both the Data Protection Act (2000) and the terms of the research ethical committee approvals were strictly adhered to at all times.

3.4. Sample

The cohort of adults with learning disabilities (n = 1, 023) living in community settings in Greater Glasgow had already been recruited into the larger longitudinal study. Due to this research project on the incidence and predictors of injuries, falls and other accidents commencing three months into the larger two-year follow up study at time 2 however (whereby 124 had already been recruited or had refused/were unable to take part), the cohort of adults with learning disabilities for this PhD research project was actually 899 potential participants.

Allowing for deaths, migration, and some potential participants choosing not to be included in the project, an estimate of the potential number of participants for this PhD research project was 600.

3.4.1. Carer Sample

As mentioned already, the adults with learning disabilities in this PhD research project were supported by their carers (support workers or relatives) during their research interviews. Being supported throughout these interviews means that, although the participants with learning disabilities were encouraged by the researchers to answer as many questions as they were able to on their own, their carers were available to answer any questions that they were unable to answer on their own on their behalf. Given that many of these participants with learning disabilities experienced communication difficulties, and were not previously known to the researchers conducting the interviews, the carers were also available to assist with communication during these interviews, as they knew the participants well.

This provided a cohort of carers to investigate the frequency, types and causes of injuries, falls and other accidents in carers of adults with learning disabilities, which is also an under-researched area. It was anticipated however, that the sample of carers would be less than the estimated potential sample size of 600 participants with learning disabilities, as some adults with learning disabilities (e.g. adults with mild learning disabilities who live independently, on their own, with no or less than 24-hours formal support) would choose not to have a carer present during their interviews.

3.4.2. Statistical Power

It was not known what proportion of the participants would have experienced at least one injury that required medical or nursing attention or treatment in the 12-month period, but it was anticipated that the proportion would be higher than the 11% previously reported by Hsieh, due to the protected living environment in that study. Hence, it was anticipated that more than 66 adults with learning disabilities would have experienced at least one injury in the 12-month period.

Consideration was given to conducting a statistical power calculation to determine the sample size that was likely to be required to detect associations between the outcomes of interest (injuries, falls with injury, frequent falls, and accidents with injury), and predictive variables. However, this was not conducted for three reasons. Firstly, the research project methodology was built upon data already held on a cohort of adults with learning disabilities recruited two years prior to the commencement of this PhD. This added strength to the project design, as most of the information on putative predictive factors was therefore prospectively collected, rather than being merely cross-sectional. The inherent

limitation is that the maximum number of participants in this PhD was therefore pre-determined and could not be increased. Within the existing literature with adults with learning disabilities, this is by far the largest study of its kind, suggesting value in it being conducted. This PhD addresses several research questions – predictive variables being just one component: based on previous research with the learning disabilities population, albeit with non-representative samples, the cohort seemed highly likely to be large enough to answer the research questions related to the incidence of falls, other accidents, and injuries associated with falls and other accidents (e.g. Hsieh et al., 2001), and also for carers, based on findings from the Scottish Health Survey 2003 (Scottish Executive, 2005). Secondly, there is almost no literature on predictors of injuries, falls and other accidents with the adult population with learning disabilities, with this study therefore necessarily being exploratory in nature. Whilst the study populations are not comparable, the study by Hsieh et al. (2001) did find some factors predictive of injury, and had a much smaller sample size than that planned in this PhD, providing some limited evidence that the cohort would be large enough to examine the factors statistically. Thirdly, whilst there is much evidence on falls with older persons in the general population, this was rejected as having minimal relevance in the planning of sample size for this population, in view of both the considerable differences in age distribution, and also the presumption that the differing range of disabilities and lifestyles and supports between the older general population and the adults with learning disabilities population would render it of limited utility.

3.5. Process

Self-report data is highly dependent on memory, comprehension, and motivation to answer truthfully (Klesges et al., 1990). Problems with acquiescence and comprehension in self-report research which is reliant on the recall of persons with learning disabilities, or even their carers by proxy, have been well documented (Finlay et al., 2001). The researchers who completed the interviews for this research project were therefore mindful of these issues throughout, and took steps to assist recall wherever possible e.g. asking participants with learning disabilities the same questions in different ways to check their understanding, and asking paid carers (support workers) to refer to written support/care plan records for details of previous injury incidents.

In preparation for conducting the research interviews at time 2, both researchers took turns to ‘shadow’ each other during the first research interviews conducted in the first month of data collection. Shadowing refers to both researchers being present during the research

interview (with the participant's permission); one to conduct the interview, and the other to observe to ensure similar interviewing techniques/styles and data collection. The researchers also shared an office for the duration of the T2 study, and set time aside each week to review/discuss each completed research interview. The same shadowing procedure was repeated with the third researcher when she joined the research team in the last two months of the study.

The three researchers responsible for T2 and injuries, falls and other accidents data collection possessed the skills necessary for interviewing and communicating with adults with learning disabilities. Janet Finlayson for example, is a registered mental health nurse (RMN) who, at the time of conducting this PhD research project, had twenty years experience of working with children and adults with learning disabilities, young/adults with mental health problems, and their carers. Janet Finlayson had recently worked on a research study which involved the design, implementation and evaluation of a training initiative for practise nurses, to increase their understanding of the health and communication needs of persons with learning disabilities (Finlayson et al., 2004; Melville et al., 2005; Melville et al., 2006). All three researchers received additional training from the consultant learning disabilities psychiatrists within the research team on e.g. completing the Vineland Scale survey, to measure each person's abilities and skills.

Individual face-to-face interviews for the larger study at T2 were conducted by the research assistants with the adults with learning disabilities and their carers. These interviews were conducted at the participant's home, or somewhere else if they preferred (e.g. a day centre). A questionnaire, which was developed for the purpose of collecting data for this PhD research project, was completed by the research assistant towards the end of each interview. The questionnaire specifically collected self-reported (and by proxy) data on injuries, accidents, and falls.

The research interviews were conducted on days and times which were convenient for the participants; most often in the afternoons once they had returned from their daytime jobs/college placements/centres, and had had enough time to unwind/relax after they had returned home (e.g. had had a cup of tea if it was part of their usual routine). Most interviews were conducted with the person's carer present; someone who knew the person well, who could assist with their communication, and answer any questions for them, that they were unable to answer on their own, by proxy on their behalf. The adults with learning disabilities were encouraged by the researcher to answer as many questions as

they were able to on their own e.g. by providing enough time for the person to answer, and repeating the same question using easier to understand language as appropriate. If at any time the adult with learning disabilities and his/her carer disagreed on the answer or details related to a specific question, then a discussion followed until their agreement was reached. In order to assist with the participant's recall, 'anchors' were used to help the person with learning disabilities remember instances of injuries, falls and accidents over the previous twelve months (e.g. 'You tell me it was your birthday/summer holiday/college graduation/parents' wedding anniversary party this time last year, did the fall you are telling me about happen before or after then?'). Anchors refer to concrete events which are easier for the person to remember, thus be more able to remember other events in relation to. Paid carers (support workers and nursing/residential care staff) were also encouraged to refer to the participant's care/support planning records in order to check written details of previous instances of injury.

The data for this PhD research project was collected towards the end of an interview which also collected data for a larger research study, whereby the interview duration was typically one hour and forty minutes; of which thirty minutes was typically spent completing the questionnaire for this PhD. Steps were taken by the researcher to avoid interview fatigue. Interview fatigue refers to the participant becoming bored, distracted or uncomfortable during the research interview. During the research interview, the participant was asked at frequent intervals (every ten to fifteen minutes) if he/she was okay, and still willing to continue. If at any time the participant indicated that/he she was not willing to continue, wanted a break, or felt uncomfortable in any way (this included the participant's non-verbal as well as verbal communication e.g. becoming restless, avoiding eye contact), then the research interview was suspended (for a break) or terminated. Participants were also given the option of continuing the research interview over two sessions if they preferred.

3.6. Materials

The following instruments were used (or utilised) to collect data on injuries, falls and other accidents for this PhD research project.

3.6.1. Working Definitions of Injuries and Falls

Data was collected on injuries that specifically required medical or nursing attention or treatment in the 12-month period. This injury definition was comparable with the same

used for published general population data on injuries (Scottish Executive, 2005). Physical injuries only were not specified, in case participants reported any psychological injuries, which could still be included according to the ICD-10.

At the time of conducting the research for this PhD project, between the years 2004 and 2006, a current definition of a fall was 'an event that results in a person coming to rest inadvertently on the ground or other level, other than as a consequence of sustaining a violent blow, loss of consciousness, sudden onset of paralysis as in stroke or epileptic seizure' (O'Neill et al., 1996). The first part of this definition was used for data collection and analyses in this research project, but the second part '…other than as a consequence of sustaining a violent blow, loss of consciousness, sudden onset of paralysis as in stroke or epileptic seizure' was not. This was due to the much higher prevalence of epilepsy in persons with learning disabilities when compared with the general population. It did not seem appropriate to ignore epilepsy-related falls from an investigation into falls experienced by adults with learning disabilities.

During the research interviews, participants were also only asked about falls in layman's terms e.g. 'Have you experienced any falls?' These interviews were being conducted with adults with learning disabilities, who can experience difficulties with communication and understanding, and their carers.

3.6.2. Questionnaire

A questionnaire was developed and used to collect self-reported and proxy-reported data on injuries, accidents and falls during face-to-face interviews. The questionnaire had to be able to collect data comparable to that within the SHS 2003 (Scottish Executive, 2005) as that was planned to be the comparable general population data in the analyses. It also needed to be able to collect data which is specific to the learning disabilities population, and so not included in the SHS data; this was informed from the literature review. A copy is included in the appendix (*appendix 8*), entitled 'Injuries, Accidents and Falls in Adults with Learning Disabilities: Home Visit Research Interview Form'. This five-part questionnaire, comprising sections A to E, is described as follows.

<u>Section A: Participant's injuries from falls, accidents, and harm</u>

Participants were asked to *estimate* how many times they had fallen within the last 12 months (including falls that resulted from epileptic seizures), to give an indication of their falls frequency; and then they were asked how many times they had been injured, and

received medical or nursing attention or treatment, as a result of a fall in the 12-month period. The same line of questioning was then repeated for accidents other than falls (e.g. road traffic accident, scalding, …), to also give an indication of their frequency of accidents other than falls, and the number of accidents other than falls that required medical or nursing attention or treatment in the 12-month period. These questions, asked separately, collected data on *unintentional* injuries, accidents and falls.

Participants were asked if they live with another person/other people who has/have challenging or problem behaviours (e.g. physical aggression or destructiveness to property). This question was most pertinent to adults with learning disabilities who live in group (shared tenancy) or residential homes. Challenging or problem behaviours refer to the same sets of behaviours (which are most often referred to in this PhD thesis as problem behaviours for ease of reading/consistency), but either of the two terms could be more familiar than the other to the adults with learning disabilities and their carers, and that is why both were used. Participants were also asked if they come into contact with another person/other people who has/have challenging behaviours anywhere else, out with his/her home (e.g. at a day centre or respite unit), and if so, where and what specific types of behaviours were they exposed to. The list of problem behaviours from the C21st Health Check was used as a prompt during these questions, as the C21st Health Check had just been completed with the adults with learning disabilities and their carers as part of the larger research study interview, thus recently explained. Participants were asked how many times they had been injured, and received medical or nursing attention or treatment, as the result of another person's/other people's challenging or problem behaviours in the last 12 months. Participants were then asked how many times they had been injured, and received medical or nursing attention or treatment, as a result of i) his/her own self-injurious behaviours and ii) his/her own problem or challenging behaviours other than self-injury in the last 12 months. The person's own problem behaviours (including self-harm/injury) had already been established during the C21st Health Check component of the larger research study interview. A box was ticked for each to indicate if the participant had none of these behaviours. These questions, again asked separately, collected data on *intentional* injuries.

The pages to follow were used to collect a detailed description of each unintentional or intentional injury that was reported, thus for each incidence of injury reported for the earlier questions there was a corresponding detailed description. Duplicate pages were included to be able to collect data on up to ten injuries incidents reported (although no

participants reported having experienced as many as ten separate injury incidents). Participants were asked to describe each injury incident by its circumstances (causative factors and precipitants), cause/s of injury, type/s of injury experienced, part (or parts) of body injured, where medical or nursing attention or treatment was sought, medical/interventions, number of days spent in hospital, where the person became injured, and whether or not any hazards were identified which contributed to the injury incident (e.g. kettle or stairs/steps). If participants experienced more than one injury at the same time, during one injury incident, then the details of each of the multiple injuries were recorded on the same injury incident page (e.g. question 3 answers 3i, bruising and 3ii, fracture).

The items on the duplicated 'Description of Injuries' page had pre-coded variables listed for the researchers to use as prompts only, if necessary. These pre-coded variables had been informed by a review of the types, causes, and circumstances of injuries known to have been experienced by these persons with learning disabilities over their life history to date, as data collected from the research nurses reviews of their medical notes as part of the larger study at time 1. The author was able to review these previously reported injuries, to help identify the likely types, causes, and circumstances of injuries experienced by this cohort. These were used to determine the data collection prompts, and it was checked that these could be compared with all the categories in the general population data which was to be used for comparison. Hence the research instrument's ability to collect data on the likely types, causes and circumstances of injuries experienced by adults with learning disabilities was maximised; some of which would later necessarily be coded into the 'other' categories when compared with the general population data, as it was not available for the general population, not being relevant to them.

Detailed descriptions of each injury incident enabled the researchers to gather as much information as possible on the potentially different characteristics of injuries experienced by adults with learning disabilities, to then code during data entry into general population pre-coded variables for the same categories, for comparison. Hence, the categories of types and causes of injuries used in the SHS 2003 (Scottish Executive, 2005) were used in the data entry, and are presented in the 'Results' chapter of this thesis, along with the 'other' causes and types of injuries reported for adults with learning disabilities. All data entry was conducted by this thesis' author.

Section B: Carer comparison

This section collected data on the carers' personal information (age, gender, and home postcode to determine area deprivation) and any injuries they had experienced in the 12-month period. Carers were asked how many times they had experienced injuries from falls, other accidents, and harm (self-harm or harm from another person) in the previous 12 months, and a detailed description of each injury incident was completed (same as for the adults with learning disabilities they care for/support). Five duplicate copies of the 'Carer Description of Injuries' page were included, although no carers reported having experienced five separate injury incidents over the 12-month period.

Section C: About Special Aids and Adaptations

This section collected data on any aids or adaptations that were in place in the person with learning disabilities home, to help prevent injuries. Eight questions asked about the following types of aids and adaptations: special flooring/carpeting; lifting aids; alarms; body protective equipment; bathroom aids; bedroom equipment; and outdoor/garden equipment. An open-ended question was included at the end, to gather data on any other aids and adaptations not already mentioned.

Section D: About risk assessments

This section collected data on formal (written) risk assessments from paid carers only (support workers or residential/nursing staff), and was only relevant to those adults with learning disabilities who lived with paid support. Paid carers were asked to list any individual (or individualised) risk assessments that had been completed for the person with learning disabilities at any time, and also to indicate whether or not the risk assessments listed had been reviewed/updated within the last 12 months. The paid carers were also asked to describe any formal training they had received on conducting risk assessments, and the formal procedures that were in place in their work place (the person with learning disabilities they support's home) for recording and reporting injuries, falls, and other accidents.

Section E: Mobility

This section collected current data on the person with learning disabilities' mobility, and included a further two questions regarding whether or not the person with learning disabilities has i) either poor balance or coordination, and ii) a tendency to be either restless or impatient.

Section F: Carer's Thoughts on Accidental Injuries and Falls

This section was completed with the carers of the adults with learning disabilities only. The questions regarded the carers' personal views (thoughts), so they were presented in an easy-to-read/understand format, to give individual carers the option of either completing this part of the questionnaire on their own (e.g. to allow time for personal reflection), or with the researcher just asking the questions and describing the format for responses (5-point Likert scale, strongly agree to strongly disagree). For those individual carers who preferred to just complete this section with the researcher, which was the majority of carers, for questions one to five they were asked, 'How strongly do you agree or disagree with the following statement…? You can strongly agree, agree, don't know, disagree, or strongly disagree.' A sixth question was included, to collect data on whether or not the carers felt that the person they care for/support is more likely to fall at a particular time of year (seasonal/weather factors). Some of these items were later included in the statistical analyses, investigating potential risk factors for injuries, falls and other accidents (more details to follow in the 'Analyses' section). These items were recoded into binary variables (agree or do not agree) for this purpose. This was because it was whether or not the carer agreed or did not agree with a particular statement that was being investigated; not level of agreement, which would have involved too small numbers in the strongly agree and strongly disagree extremities.

At the end of the questionnaire, the adults with learning disabilities and their carers were asked if they had any additional comments about injuries, falls and other accidents that they wished to make, and space was provided for the researcher to record their additional comments. The participants were also asked whether or not they would like to receive a summary of the results towards the end of this PhD research project (a tick box was included to record their response).

This semi-structured questionnaire was the main instrument for data collection for this PhD research project on injuries, falls and other accidents. This questionnaire was purpose-designed to be able to collect as much data possible on the likely types, causes and circumstances of injuries experienced by adults with learning disabilities (informed by a review of previous injuries the cohort of persons with learning disabilities were known to have experienced,), and then be directly comparable with most contemporaneous Scottish general population data for the same in the most SHS 2003 sample (Scottish Executive, 2005). The evidence from the literature review also demonstrates that other instruments or measures which are used more routinely with people in the general population may not

have been suitable, because they are not tailored for use with people with learning disabilities, and require design modification (Sherrard et al., 2004; Hale et al., 2007). No other additional instruments or measures were introduced for data collection; this was due somewhat to constraints on interview time.

3.6.2.1. Questionnaire Pilot

The questionnaire was piloted with six support workers, who were working in a cluster of three supported living group homes for two to four adults with learning disabilities, a few miles out with the geographical research area of Greater Glasgow. This pilot work was conducted to check the usability of the questionnaire and the validity of its content (Bowling, 2002). By prior arrangement, eight copies of the questionnaire were posted to the support workers' project/line manager who distributed them, and they were completed by all six support staff workers who were on shift at that particular time, and willing to take part (the number of support workers per shift ranged from between six and eight). Written instructions were included, asking the support workers to report individually on the content of the questionnaire (e.g. were the questions easy or difficult to understand and answer?), its suitability for use with the adults with learning disabilities they support, its usability overall (e.g. language use), and the amount of time taken to answer all of the questions. No problems or difficulties with the questionnaire were reported by the support workers, four of whom had each completed the questionnaire with the person with learning disabilities they were key-worker to (designated person responsible for their care/support planning), and the reported time taken to complete the questionnaire ranged from between ten and twenty five minutes, which was reported to be acceptable. Review of the completed questionnaires, all of which were returned along with the support workers' written comments, demonstrated that the actual data collected was in accordance with i) the author's/researcher's expectations of the data that would be collected (e.g. enough descriptive information to determine the types, causes and circumstances of injuries experienced in the previous 12 months) (face validity); and ii) the project manager's subsequent review of the six adults with learning disabilities' concerned support/care plans for documentary evidence of previous injuries reported (content validity), which was also requested. No amendments were required to be made to the questionnaire as a result of this pilot.

3.6.3. General Population Data for Comparison

The Scottish Health Survey gathers periodic national and regional data from surveys and interviews of almost 12, 000 adults and children in Scotland, and provides information on the trends of certain measures of health (e.g. smoking, alcohol consumption, physical activity, and accidents). Data is collected from across seven regional Health Board areas: Highlands and Islands; Grampian and Tayside; Lothian and Fife; Borders, Dumfries and Galloway; Greater Glasgow; Lanark, Ayrshire and Arran; and Argyll, Clyde and Forth Valley.

The SHS 2003 (Scottish Executive, 2005) provides published data on the types and causes of non-fatal injuries, accidents and falls that required medical or nursing attention or treatment in a 12-month period for 8, 148 adults in the Scottish general population, which includes 1, 225 adults in the Greater Glasgow area.

The SHS 2003 Scottish general population sample does include twenty persons with learning disabilities, two of whom (10%) had experienced at least one injury in the previous twelve months; one had experienced a bone fracture following a fall, and the other had experienced cuts/grazes on two occasions and bruising/pinching a part of the body on one occasion as a result of falls. However, none of these adults with learning disabilities were living in the Greater Glasgow area.

The SHS 2003 data set was accessed electronically, so that the types and causes of injury experienced by the adults with learning disabilities and their carers over a 12-month period could be compared with the same for the Greater Glasgow sub-sample of adults in the SHS 2003. The SHS 2003 types and causes of injury categories were utilised for this purpose:

- Types of injury: broken bones; dislocated joints; losing consciousness; straining or twisting a part of the body; cutting or grazing a part of the body; bruising or pinching a part of the body; object stuck in a part of the body e.g. ear; burning or scalding; poisoning; internal injury; animal or insect bite or sting; swelling or tenderness; and other types.
- Causes of injury: Fall, trip or slip; hit by a falling object; road traffic accident; sports or recreational accident; use of a tool, implement or equipment; animal or insect bite or sting; another person (e.g. attacks); lifting; and other causes.

Of the 1, 225 adults in the Greater Glasgow area in the SHS, 936 adults were aged 18 – 64 years. Their data was extracted for the comparator data, in view of the difference in age

distributions between the adults with learning disabilities and the general population, with there being few adults with learning disabilities aged over 65.

The data from the carers of the adults with learning disabilities in this study were compared with 1, 225 adults in the SHS 2003 Greater Glasgow sub-sample (aged 18 years and over). The carers sample comprised both working age adults (paid carers) and older parents of the adults with learning disabilities (unpaid carers).

3.6.4. Data from T1 Materials Utilised

T1 baseline data was utilised to analyse and identify predictive risk factors for injuries, falls and accidents other than falls. The selection of variables was informed by the literature reviews. The specific data utilised was the following 22 variables.

Demography questionnaire:

Personal and lifestyle/supports information (seven variables): age (numeric); gender (male or female); level of learning disabilities (mild, moderate, severe or profound); lives with (family carer, independently, paid support or congregate care); area deprivation (Carstairs quintiles, 1, most affluent to 5, most deprived); person has a job, day centre or college placement (yes or no); and whether or not the person smokes (yes or no).

C21st health check:

Physical health information provided by the C21st health check, which incorporates data collected from a review of medical notes and a physical examination (eleven variables): person has a visual impairment (yes or no); person has hearing impairment (yes or no); person has bowel incontinence (yes or no); person has urinary incontinence (yes or no); person has impaired mobility (yes or no); person has a foot/toe deformity (yes or no); person has epilepsy (yes or no); person's measured body mass index (BMI) (underweight <BMI 18.5, acceptable weight 18.5≥ BMI <25, overweight 25≥ BMI <30, obese ≥30 BMI <35, or morbidly obese BMI >35); person has special communication needs (yes or no); person has Down syndrome (yes or no); and number of prescribed drugs (> 3 drugs).

Mental health assessment:

Mental health information provided by the C21st health check and the PAS-ADD Checklist, and the comprehensive mental health assessment by the consultant learning disabilities psychiatrists in the research team (four variables): person has a mental health problem (yes or no); person has autism (yes or no); person has problem behaviours (yes or

no); and number of adverse life events experienced within the previous 12 months (numeric).

Hence the 22 potential risk factors measured at T1 were:

- 3 personal factors: age; gender; and level of learning disabilities
- 5 items on lifestyle and supports: accommodation type; no daytime job/occupation; Carstairs deprivation quintile; person smokes; and number of life events experienced in 12-month period.
- 14 items on health and disabilities: visual impairment; body mass index (BMI); hearing impairment; bowel incontinence; urinary incontinence; impaired mobility; foot or toe deformity; epilepsy; special communication needs; Down syndrome; autism; problem behaviour/s; mental ill-health; and number of prescribed drugs.

3.6.5. Data from T2 Materials Utilised

Data collected via the demography questionnaire at T2 was also utilised.

The following items were used to report the current demographics/characteristics of the sample in this PhD research project: age (mean, range and standard deviation); marital status (married/live-in partner, separated/divorced, single or widowed); ethnicity (e.g. Caucasian, Pakistani, Chinese); level of learning disabilities (mild, moderate, severe or profound); and lives with (family carer, independently, paid support, or congregate care). A copy of these questionnaire questions is included in the appendix (*appendix 9*).

Additionally, three items were included in the analyses for the purpose of identifying associated risk factors for injuries, falls, and other accidents. These items were:

- Person uses public transport as their primary mode of transport (yes or no);
- Person's physical activity level (active or inactive), which was a re-coded binary variable based on each person's self-reported (or reported by proxy) SHS 2003 summary physical activity level (Finlayson et al., 2009); and
- Whether or not the person was wearing poorly fitting shoes (yes or no).

Whether or not the person was wearing poorly fitting shoes was determined by comparing the size of his/her most frequently worn (favourite) pair of shoes with his/her actual (measured) shoe size.

Hence, there were 9 potential risk factors measured at T2:

- 3 items on disabilities: poor balance/coordination; restless/impatient; and clumsy/accident-prone.
- 2 items on care's opinions: carer thinks most accidents are not preventable; and carer thinks person has a fear of falling.
- 4 items on activities: person uses public transport; physical activity level; injury related to season/weather; and poorly fitting shoes.

3.6.6 Rationale for T1 and T2 Variable Selection

Of 22 main risk factors identified for falls in older adults that were summarised in the World Health Organization's (2008a) 'Global Report on Falls Prevention' (table 1.1), eight were investigated in this PhD research project as potential predictive (T1) risk factors for falls/injuries in adults with learning disabilities; namely, age, gender, area deprivation (socio-economic status), visual impairment, urinary incontinence, foot/toe deformity (foot problems), body mass index (weight), and number of prescribed drugs. A further four (poor gait/balance, sedentary behaviour, fear of falling/self-efficacy, and poorly fitting shoes) were investigated as potential associated (T2) risk factors. Of the remaining ten main risk factors identified for falls in older adults, six were either not as relevant for this cohort of adults with learning disabilities and/or were subject to very low prevalence; namely, ethnicity, diabetes, Parkinson's disease, Alzheimer's disease, depression and alcohol misuse, thus not tested. Muscle weakness was not assessed at T1 or T2, and neither was stairs/steps established as a significant environmental hazard/risk factor for falls/injuries in this cohort. Additionally, mental ill-health (of any type) was investigated as a potential predictive (T1) risk factor. The available T1 data on previous history of falls had not been systematically investigated so was not considered robust enough to use. Cognitive impairment was not tested but level of learning disabilities was (mild, moderate, severe or profound).

Drawing from the limited research on persons with learning disabilities, fourteen risk factors previously identified for falls/injuries in persons with learning disabilities were visual impairment/blind (Sherrard et al., 2002; Wagemans et al., 2006), hearing impairment/deaf (Sherrard et al., 2002), overly sociable temperament (Sherrard et al., 2002), problem behaviours (Konarski et al., 1997; Sherrard et al., 2002), epilepsy (Sherrard et al., 2002; Wagemans et al., 2006; Chiba et al., 2009), frequency of epileptic seizures (Konarski et al., 1997; Hsieh et al., 2001), antipsychotic drugs (Konarski et al., 1997; Hsieh et al., 2001; Wagemans et al., 2006), being mobile/immobility (Sherrard et al., 2002;

2002; Hsieh et al., 2001; Wagemans et al., 2006), older age (Hsieh et al., 2001; Wagemans et al, 2006; Chiba et al., 2009), paretic conditions (Chiba et al., 2009), hemiplegia (Wagemans et al., 2006), previous fractures (Wagemans et al., 2006), ability level (Konarski et al., 1997), and co-morbid symptoms (Grant et al., 2001). Seven of these were investigated as potential (T1) predictive factors for falls/injuries in this cohort of community-based adults with learning disabilities; namely, age, ability level, epilepsy, problem behaviours, visual impairment, hearing impairment, and impaired mobility (mobility problems). The remaining seven risk factors identified in the learning disabilities literature were not investigated (overly sociable temperament due to lack of T1 data, antipsychotic drugs as number of drugs taken was used instead, co-morbid symptoms due to lack of precision of this term, frequency of epileptic seizures as presence of epilepsy was used instead, and previous fractures due to incomplete data at T1, and paretic conditions/hemiparesis due to their low prevalence), but restlessness and/or impatience was tested as a potential (T2) factor (Wazana, 1997).

In addition to those previously reported, eight potentially predictive (T1) risk factors for falls/injuries were investigated in this PhD research project, many of which have particular relevance to the population with learning disabilities; living arrangement (lives with), no job (whether or not the person has daytime activities), special needs in communication, Down syndrome, autism, whether or not the person smokes, bowel incontinence, and number of adverse life events in the previous 12 months. A further four potentially associated (T2) risk factors for falls/injuries were investigated; whether or not the person is clumsy/accident-prone, whether or not the person is a public transport user, whether or not the person's carer thinks most accidents are *not* preventable, and whether or not the person is more likely to injure him/herself in a particular season (in Winter, due to snow and ice, or in Summer, due to being more active outdoors). Whether or not the person is a public transport user could be indicative of their level of community participation. Whether or not the person's carer thinks most accidents are *not* preventable was included, to explore a possible association between a lay person's different perspective (from that of the public health view) on whether or not accidents are preventable and incidence of accidents (Girasek, 1999). Whether or not the person is thought to be clumsy or accident-prone was investigated for the same reason, as the literature demonstrates that the notion of accident-prone individuals is a myth, but individuals who experience frequent accidents/injury can be more likely to have predisposing factors, such as hyperactivity. Restlessness/impatience is a main symptom of hyperactivity (Langley, 1982; Wazana, 1997). Seasonal factors were

also included because the relationship to falls frequency is suggested in the falls literature (Lord et al., 2007).

A summary of the factors considered for inclusion in the analyses is presented in *table 3.1.*

Table 3.1. Risk/Factors Considered for Inclusion in the Analyses for this PhD Research Project (2 pages)

I. Factors identified from literature on older adults in the general population
Included in T1 analyses: Age Visual impairment Gender Socio-economic status (area deprivation) Urinary incontinence Foot/toe deformity (foot problems) Body mass index Polypharmacy (> 3 prescribed drugs) Mental ill health (of any type, rather than specifically depression or Alzheimer's disease)
Included in T2 analyses: Poor gait/balance Sedentary behaviour (inactivity) Fear of falling Poorly fitting shoes
Occurring at too low prevalence in the T1 data to include in the analyses: Ethnicity Diabetes Parkinson's disease Alcohol misuse Alzheimer's disease Depression (although T1 mental ill-health was included)
No suitable data collected to include in the analyses: Muscle weakness Stairs/steps Cognitive impairment (although T1 level of learning disabilities was included) Previous history of falls (as T1 data was not considered sufficiently robust on this variable)
II. Factors identified from literature on persons with learning disabilities:

Included in T1 analyses: Age Visual impairment Level of learning disabilities Epilepsy Problem behaviours Hearing impairment Impaired mobility (mobility problems)
Occurring at too low prevalence in the T1 data to include in the analyses: Hemiplegia Cerebral palsy
No suitable data collected, or other similar data included in the analyses: Overly sociable temperament (althoughT2 restlessness/impatience was included) Antipsychotic drugs (as T1 polypharmacy was included) Previous fractures (as T1 data was not considered robust enough on this variable) Co-morbid symptoms (due to lack of precision of the term) Frequency of epileptic seizures (presence of epilepsy was used instead)
III. Additional factors considered as putative predictors:
Included in T1 analyses: Living arrangement (accommodation type) No job or daytime activities (e.g. day centre or college placement) Special needs in communication Down syndrome Autism Smoker Bowel incontinence Number of life events in previous 12 months
Included in T2 analyses: Restlessness/impatience Clumsy/accident-prone Public transport user Carer thinks most accidents are *not* preventable Seasonal/weather factors

3.7. Analyses

The statistical plan was devised following the advice of an experienced statistician at the Robertson Centre for Biostatistics, University of Glasgow. Quantitative data was analysed using the statistical computer package SPSS Version 14, to answer each one of the research questions as follows.

Research question 1: What is the incidence of unintentional and intentional injuries and falls in adults with learning disabilities over a 12-month period?

Frequency data was calculated to provide the number and percentages of participants who had, over the 12-month period, experienced:

a) at least one injury,

b) at least one unintentional injury,

    i) at least one unintentional injury due to falls (both falls of all causes, and falls excluding epilepsy-related falls),

    ii) at least one unintentional injury due to accidents,

c) at least one intentional injury,

    i) at least one intentional injury due to other people's problem behaviour/s,

    ii) at least one intentional injury due to self-injury,

d) at least one fall with or without injury.

In view of an anticipated high rate of falls, frequency data was then calculated to show the distribution of:

a) number of incidents of falls, with or without injury,

b) number of incidents of injury,

Research question 2: What are the types and causes of unintentional and intentional injuries and falls experienced by adults with learning disabilities over a 12-month period?

Frequency data was calculated to provide the number and percentage with each different type of unintentional and intentional injury, and for their causes.

Some people had had more than one of a specific type or cause of injury. Hence types and causes of injury are reported as when they were experienced at least once. For example:

- If one of the adults experienced one incidence of burns caused by scalds and one incidence of a fall which resulted in a bone fracture in the 12-month period, then scalds and a fall (causes) and burns and fracture (types) were all counted as having been experienced at least once.
- If one of the adults experienced one incidence of a fall, which resulted in a cut to his/her head and concussion, then a fall (cause) and cut and concussion (types) were all counted as having been experienced at least once.
- If one of the adults experienced two separate falls which resulted in a bone fracture on one occasion and a cut to a part of the body on the other however, only one fall was counted as a cause experienced at least once, and both bone fracture and cut to a part of the body were counted as types experienced at least once.

Research question 3: Are adults with learning disabilities more prone to injuries, accidents and falls, when compared with published general population data?

The sub-sample of participants aged 18-64 years was selected so that they could be compared with the 936 Greater Glasgow region participants in the Scottish Health Survey. For these adults in the SHS sub-sample, the incidence of injury was 12.5% (117 people). Based on this same region SHS 2003 rate, the number of adults with learning disabilities who were expected to have incident injury was calculated, and the expected number compared with the observed number through calculating the standardized incident ratio, with 95% confidence intervals.

Comparison of each different type of injury, and their causes was then made between the participants with learning disabilities, and those in the SHS 2003 Greater Glasgow sub-sample, by calculating frequency data, and conducting inferential statistical analyses using the χ^2 (Chi-squared) statistical test. The Chi-squared statistical test is used for categorical (non-numeric) data.

Research question 4: Can demographic, lifestyle, health and disabilities factors be identified as risk factors for injuries, accidents, and falls of adults with learning disabilities?

These analyses focused on the dependent outcomes of incident injury, and incident unintentional injury, and not incident intentional injury, given that the proportion of participants with incident intentional injury was anticipated to be very small. The 22

potential risk factors measured at T1, and the 9 potential risk factors measured at T2 were selected on the basis outlined in section 3.6.6.

Initially, the distribution of the outcomes of interest and each factor was assessed individually, to determine the strength of associations. This was conducted using χ^2 statistical tests and 2-sided student t-tests. Two-sided student t-tests are used for continuous numeric data (e.g. age). However, the author of this PhD thesis considered it highly likely that at least some of the factors would interact/overlap, and so from outset planned to use multivariate logistic regression modelling to take account of interactions. For example, autism is more common in men than women, and in people at lower levels of ability. Hence if e.g. both autism and male gender were found to be predictive of accidents, then the finding for autism might be entirely or largely due to the higher rate of male gender in the group with autism rather than due to the autism per se. By first presenting the data to show the univariate association of each outcome with the potential risk factor, followed by multivariate logistic regressions, this issue of individual versus independent relationships is highlighted.

Stepwise binary logistic regression analysis was used for the second stage of the statistical analyses, which is the preferred method for this type of exploratory analyses (Menard, 1995). The investigation of predictive factors was essentially an exploratory study, as there is almost no previous literature on this topic in this population. Hence a stepwise method was used for the multivariate regression, to be sensitive to potential predictors. The aim in fitting these regression models was not to derive a clinically predictive tool, but to assess a broad range to factors that are potentially related with incidence in this population. Consequently, measures of discriminatory ability are not reported, nor any cross-validation of these models, as would have been appropriate was there an attempt to derive a prognostic tool. The intention is that these findings will stimulate and guide future research in this area, whether epidemiological or interventional.

Using a single stepwise procedure to arrive at a final model for each outcome is somewhat arbitrary. Hence the analyses were repeated using alternative methods (forward and backward stepwise procedures) and the results considered in the context of clinical understanding.

The potential risk factors (22 from T1 and 9 from T2) were analysed for predicting which individuals would experience the following five outcomes:

- Incident injury
- Incident falls with injury
- Incident falls with injury, excluding epilepsy-related falls
- Repeated falls (≥ 3 falls), with or without injury
- Incident accidents other than falls with injury.

Following the first stage of the analyses to determine the distribution of the outcomes of interest and each putative related factor individually using χ^2 tests and 2-sided student t-tests, then the multivariate regression modelling was used. This was done separately for the T1 factors, and then done for the T2 factors. This separation of T1 and T2 factors was to increase the robustness of the analyses, given that the T1 factors were prospectively collected data, whereas the T2 factors data was only collected on cross-section.

The individual T1 predictors that were identified from the first stage analyses (χ^2 tests and 2-sided student t-tests), were entered into a multivariate regression model and a backward stepwise method was used for each of the five outcomes (incident injury, incident falls with injury, incident falls with injury excluding epilepsy-related falls, repeated falls, and incident accidents with injury). This was then repeated using a forward stepwise method. Likelihood ratio tests were used in the stepwise procedures to determine statistical significance for removal of each factor (the removal criterion was set at 0.05). The odds ratios and 95% confidence intervals were tabulated for each of the factors which were retained in the final regression model for each of the five outcomes.

The same procedure was then repeated for the individual T2 associated factors from the first stage analyses (χ^2 tests and 2-sided student t-tests). They were entered into a multivariate regression using both backward and forward stepwise methods for each of the five outcomes (incident injury, incident falls with injury, incident falls with injury excluding epilepsy-related falls, repeated falls, and incident accidents with injury). Likelihood ratio tests were again used in the stepwise procedures to determine statistical significance for removal of each factor (the removal criterion was set at 0.05).

Research question 5: What factors are perceived by adults with learning disabilities and their carers as contributing to injuries, accidents and falls of adults with learning disabilities?

Hazards identified by the adults with learning disabilities and their carers, as having contributed to the injury incidents they reported, were labelled and data entered according to their reported descriptions (e.g. a kettle, or stairs/steps). Each type of hazard identified was reported by the frequency and percentage (proportion) of the sample who had reported it.

Research question 6: To what extent are aids and adaptations, risk assessments, and incident reporting utilised?

Types of aids and adaptations, risk assessments and incident reporting procedures were labelled and data entered according to their reported descriptions (e.g. shower seat as a bathroom aid, and a risk assessment for using public transport). Frequency data was then calculated to provide the numbers and percentages of different types of aids and adaptations in situ, risk assessments conducted by paid carers (including whether or not they had been revised or updated within the previous 12 months), and paid carers' incident reporting procedures.

Research question 7: Are carers of adults with learning disabilities more prone to injuries, accidents and falls when compared with a) the adults with learning disabilities they support and b) published general population data?

Frequency data for types and causes of injuries experienced by the carers of the adults with learning disabilities were calculated, and then compared with the same for a) the adults with learning disabilities they care for/support, and b) the Greater Glasgow general population sub-sample in the SHS 2003 (aged 16 years and over). Comparisons were also made between unpaid carers and paid carers, who have different characteristics.

Summary

This chapter has described the methodology and methods employed for this PhD research project on injuries, falls and other accidents in adults with learning disabilities, both in relation to the previous literature and the research gap it has attempted to address, and the

context of the research environment and larger longitudinal study it was built on to. The results of the analyses of the data collected through research interviews are reported in the next chapter to follow.

The methodological implications of this research project, and the strengths and limitations of the methods employed, are given further consideration in the 'Discussion' chapter.

CHAPTER 4:
RESULTS

Overview

The data collected and analysed for this PhD research project are presented in this chapter. After first presenting the cohort characteristics and investigating how representative it is compared with non-participants, these results are reported in order of the research questions 1 to 7 which they answer.

4.1. The Incidence of Injuries and Falls Experienced by Adults with Learning Disabilities

4.1.1. Cohort Characteristics: Participants and Non-Participants

The T1 cohort comprised 899 participants. At T2, 99 were excluded, due to death (34), too ill/dying to participate (5), other circumstances precluding participation e.g. recent parental bereavement (8), incomplete data collection before end of project (5), and impossibility to meet the Adults with Incapacity (Scotland) Act requirements due to having no known next of kin (47). Therefore potential cohort size was 800, of whom 197 (24.6%) declined to participate, 85 (10.6%) did not respond to the invitation to participate, and 7 (0.9%) did not provide injuries, falls and accidents information. Hence 511 (63.9%) participants participated at both T1 and T2 (*figure 4.1*).

The characteristics of participants who completed the study at T2 are shown in *table 4.1*. They were not statistically different in terms of characteristics compared with those who declined to participate (also shown in *table 4.1*).

Figure 4.1. T1 Participants Completing Study at T2

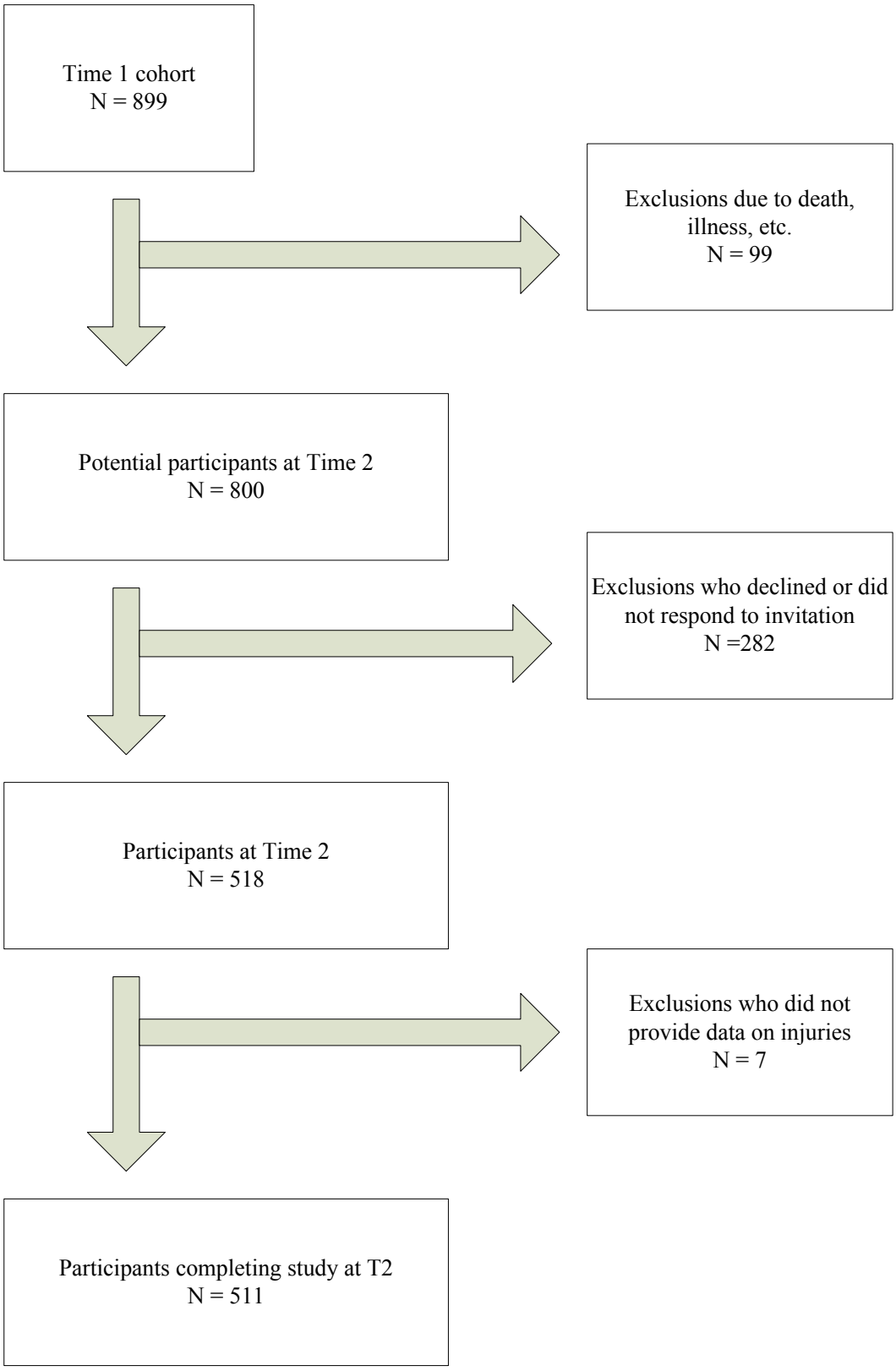

Table 4.1. Characteristics of Participants Compared With Non-Participants

Characteristic		**Whole cohort who participated**	**Non-participants who refused to participate at T2**	**χ^2/t-test**	**Significance**
		511 (100%)	**197 (100%)**		
Gender	Male	273 (53.4%)	111 (56.3%)	0.449	P = 0.503
	Female	238 (46.6%)	86 (43.7%)		
Level of learning disabilities	Mild	201 (39.3%)	81 (41.1%)	2.543	P = 0.468
	Moderate	117 (22.9%)	48 (24.4%)		
	Severe	97 (19.0%)	37 (18.8%)		
	Profound	96 (18.8%)	31 (15.7%)		
Type of accommodation/support at T1	Lives with paid support	230 (45.0%)	86 (43.7%)	9.245	P = 0.436
	Lives with family carer	218 (42.7%)	72 (36.5%)		
	Lives independently	44 (8.6%)	22 (11.2%)		
	Congregate care	19 (3.7%)	17 (8.6%)		
Age at T1	Mean	43.7 years	44.4 years	-1.076	P = 0.282
	Range	16 – 79 years	18 – 79 years		
	Standard deviation	14.2 years	14.2 years		

4.1.1.1. Consent/Consent by Proxy

Two hundred and seventy (52.8%) of the adults with learning disabilities were able to give their own consent to participate in this research project (201 adults with mild learning disabilities, and 69 with moderate learning disabilities). Two hundred and forty-one (47.2%) of the adults with learning disabilities were only able to participate as much as they were able to with their nearest relative's/welfare guardian's consent by proxy (48 adults with moderate learning disabilities, 97 with severe learning disabilities, and 96 with profound learning disabilities). Only two of the adults with learning disabilities in the whole cohort had an appointed welfare guardian.

4.1.1.2. Gender of Participants, and Demographics by Gender

The ratio of 273 (53.4%) males to 238 (46.6%) females with learning disabilities was as expected, given that the ratios for typical cohorts of children and young people with learning disabilities are about 60% male and 40% female, which become more equal through advancing age (NHS Scotland, 2005; page 17). There were no significant differences in age at T2, marital status, ethnicity, level of learning disabilities, and type of accommodation/support between the men and women in the sample (*table 4.2*.).

Table 4.2. Cohort Demographics by Gender (N = 511)

	Men **273 (100%)**	**Women** **238 (100%)**	**χ^2/t-test**	**Significance**
Age at T2:				
Mean (range; standard deviation)	48 years (23-81; 14.76)	45 years (18-81; 13.74)	1.686	P = 0.153
Marital status:				
Single	270 (98.9%)	222 (93.3%)	11.607	P = 0.09
Married/live-in partner	2 (0.7%)	8 (3.4%)		
Separated/divorced	1 (0.4%)	5 (2.1%)		
Widowed	0 (0%)	3 (1.3%)		
Ethnicity:				
Caucasian	267 (97.8%)	232 (97.5%)	3.216	P = 0.667
Pakistani	4 (1.5%)	3 (1.3%)		
Chinese	1 (0.4%)	1 (0.4%)		
Sikh	1 (0.4%)	0 (0%)		
Black Caribbean	0 (0%)	1 (0.4%)		
Bangladeshi	0 (0%)	1 (0.4%)		
Level of LDs:				
Mild	98 (35.9%)	103 (43.3%)	4.612	P = 0.203
Moderate	64 (23.4%)	53 (22.3%)		
Severe	60 (22.0%)	37 (15.5%)		
Profound	51 (18.7%)	45 (18.9%)		
Accommodation type:				
Lives with paid support	127 (46.5%)	103 (43.3%)	0.841	P = 0.840
Lives with family carer	112 (41.0%)	106 (44.5%)		
Lives independently	23 (8.4%)	21 (8.8%)		
Congregate care	11 (4.0%)	8 (3.4%)		

4.1.1.3. Cause of Learning Disabilities

For the majority of the sample (59.7%), the cause of their learning disabilities was unknown (*table 4.3*).

Table 4.3. Cause of Adults' Learning Disabilities

Cause of learning disabilities	N = 511 (100%)
Unknown	305 (59.7%)
Genetic:	117 (23.0%)
Down's syndrome	*103 (20.2%)*
Tuberous Sclerosis	*4 (0.8%)*
Phenylketonuria (PKU)	*2 (0.4%)*
Prader-Willi syndrome	*1 (0.2%)*
Rett syndrome	*1 (0.2%)*
Rubinstein-Taybi syndrome	*1 (0.2%)*
Bardet Bieldi	*1 (0.2%)*
Other chromosomal abnormality	*4 (0.8%)*
Pre-natal/neo-natal:	50 (9.8%)
Birth injury	*32 (6.3%)*
Pregnancy complications (e.g. eclampsia)	*15 (2.9%)*
Premature birth	*1 (0.2%)*
Foetal alcohol syndrome	*1 (0.2%)*
Congenital syphilis	*1 (0.2%)*
Infective:	13 (2.5%)
Meningitis/encephalitis	*12 (2.3%)*
Tuberculosis (TB)	*1 (0.2%)*
Neuro/developmental:	14 (2.6%)
Microcephaly	*3 (0.6%)*
Craniostenosis	*1 (0.2%)*
Hydrocephalus	*10 (2.0%)*
Acquired:	7 (1.4%)
Head injury	*5 (1.0%)*
Cerebral haemorrhage	*2 (0.4%)*
No response/missing	5 (1.0%)

4.1.2. The Incidence of Injuries and Falls in Adults with Learning Disabilities over a 12-Month Period

4.1.2.1. Incidence of Injuries, Accidents and Falls

The incidence of at least one injury that required medical or nursing attention/treatment in the 12-month period was 20.5% (105 people) for the whole sample (n = 511). The incidence was higher at 22.1% (113 people) if self-injury is included.

Regarding unintentional injury, incident injury due to falls was 12.1% (62 people), falls excluding epilepsy-related falls was 10.4% (52 people), and due to accidents (other than falls) was 8.4% (43 people).

Regarding intentional injury, incident injury due to other people's problem behaviours was 1.0% (5 people), and due to self-injury was 2.3% (12 people).

Falls were common: 40.1% (205 people) had experienced at least one fall with or without injury in the previous 12 months, 115 (22.5%) more than once. Accidents other than falls with or without injury had an incidence of 11.5% (59 people).

4.1.2.2. Falls Frequency

Of the 40.1% (205 persons) who experienced at least one fall with or without injury in the 12-month period, 109 (39.9% of 273) were men and 96 (40.3% of 238) were women (*table 4.4*).

Table 4.4. The Adults with Learning Disabilities who Experienced at Least One Fall With or Without Injury

	Adults with Learning Disabilities N = 205	**χ^2/t-test**	**Significance**
Gender:			
Male	109	5.985	P = 0.479
Female	96		
Age (in years):			
Mean	47	1.198	P = 0.174
Range	20 – 77		
Standard Deviation	14.051		
Level of LDs:			
Mild	85	5.853	P = 0.119
Moderate	54		
Severe	30		
Profound	36		
Accommodation Type:			
Lives with family	87	4.877	P = 0.181
Lives with paid support	87		
Lives in congregate care	12		
Lives independently	19		

One hundred and fifteen (22.5%, 67 men and 46 women) had fallen with or without injury more than once in the 12-month period. Frequency data is provided in *table 4.5*. The three who had fallen at least daily had fallen 365 times, 1, 560 times, and 1, 820 times individually. Thus, eighty-six (16.8%) adults with learning disabilities experienced repeated falls (three or more) with or without injury in the 12-month period.

There was no statistical difference between gender and the number of times fallen with or without injury in the 12-month period ($t = 0.327$; $df = 509$; $p = 0.744$).

Table 4.5. Falls frequency

Number of Incidents of Falls (with or without Injury) in the 12 month period	Frequency N = 511 (100%)
0	306 (59.9%)
1	90 (17.6%)
2	29 (5.7%)
3-11	46 (9.0%)
12-51 (monthly)	21 (4.1%)
52-364 (weekly)	16 (3.1%)
365+ (daily)	3 (0.6%)

4.1.2.3. Total Number of Injuries Reported by Adults with Learning Disabilities

One hundred and thirteen (22.1%) adults with learning disabilities experienced a total number of 140 injury incidents (self-injury included) in the 12-month period. Some adults with learning disabilities experienced more than one incidence of injury (*table 4.6*).

Table 4.6. Total number of Injury Incidents (Self-Injury Included) Experienced by Adults with Learning Disabilities in the 12-Month Period

Number of Instances of Injury in the 12-Month Period	Injured Adults with Learning Disabilities N = 511 (100%)
0	398 (77.9%)
1	93 (18.2)
2	15 (2.9%)
3	4 (0.8%)
4	1 (0.2%)

Of the 140 separate incidences of injury reported, some resulted in more than one injury being sustained at one time e.g. a person sustained a cut to his/her head and concussion at the same time. The total number of injuries reported therefore, was 148 injuries.

In this section results are reported according to either total number of injury incidents (n = 140) or total number of injuries sustained (n = 148) in the 12-month period, as described in section 3.7 of the methods.

4.1.2.4. Where Adults with Learning Disabilities Sought Medical or Nursing Attention/Treatment

Table 4.7 shows the source of medical or nursing attention or treatment that was sought by/given to the 113 adults with learning disabilities who became injured on 140 separate occasions: medical attention/treatment was mostly sought from an Accident and Emergency Hospital Department.

Table 4.7. Where Medical or Nursing Attention/Treatment was Sought by Adults with Learning Disabilities

	Number of incidences of injury reported N = 140 (100%)
Hospital but not general practitioner (GP)	82 (58.6%)
GP but not hospital:	33 (23.6%)
GP	*28 (20.0%)*
Practice nurse	*5 (3.6%)*
GP and hospital	5 (3.6%)
Other:	20 (14.2%)
First aid worker	*12 (8.6%)*
Pharmacist	*2 (1.4%)*
Nurse on site	*2 (1.4%)*
Family/friend with medical expertise	*2 (1.4%)*
Epilepsy nurse specialist	*1 (0.7%)*
Police surgeon	*1 (0.7%)*

4.1.2.5. Adults with Learning Disabilities Number of Days Spent in Hospital

Twenty-one (18.6%) of the 113 adults with learning disabilities who experienced at least one injury incident in the 12-month period were admitted to hospital following injury. The total number of days spent in hospital was 112 bed days cumulatively (*table 4.8*).

Table 4.8. Adults with Learning Disabilities Number of Days Spent in Hospital

Number of Days	**Proportion of Adults with LDs Admitted to Hospital N = 21 (100%)**
1	9 (42.9%)
2	2 (9.5%)
3	5 (23.8%)
7	1 (4.7%)
14	1 (4.7%)
21	1 (4.7%)
42	1 (4.7%)

4.1.3. Section Summary

The results in this section have reported the characteristics of the community-based cohort of adults with learning disabilities who participated in this research project, as well as the incidence of injuries (self injury excluded and included) and falls over a 12-month period. These results answer research question 1, 'What is the incidence of unintentional and intentional injuries and falls in adults with learning disabilities over a 12-month period?'

Injuries and falls with or without injury were common in this cohort (experienced by 22.1% and 40.1% respectively in the 12-month period). Falls were the commonest cause of injury, epilepsy-related falls included (62 people, 12.1%) and excluded (52 people, 10.4%).

4.2. The Types and Causes of Injuries and Falls Experienced by Adults with Learning Disabilities

4.2.1. Types of Injury

The types of injury experienced at least once in the 12-month period by adults with learning disabilities are reported in *table 4.9*.

Table 4.9. Types of Injury Experienced at Least Once in a 12-Month Period by Adults with Learning Disabilities (Self-Injury Excluded)

SHS 2003 Categories	Whole Cohort N = 511 (100%)
Broken bones	16 (3.1%)
Dislocated joints	3 (0.6%)
Losing consciousness	7 (1.4%)
Straining or twisting part of body	7 (1.4%)
Cutting or grazing part of body	38 (7.4%)
Bruising or pinching part of body	26 (5.1%)
Object stuck in part of body e.g. ear	1 (0.2%)
Burning or scalding	9 (1.8%)
Poisoning	4 (0.8%)
Internal injury	0 (0%)
Animal/insect bite or sting	1 (0.2%)
Swelling or tenderness	19 (3.7%)
Other	1 (0.2%)*
Any type	105 (20.5%)

* Near drowning

4.2.2. Causes of Injury

The causes of injury experienced at least once in the 12-month period by adults with learning disabilities are reported in *table 4.10.* 'Other' causes of injury experienced by 18 adults with learning disabilities were: poisoning (e.g. drug administration error) 3 (0.6%); carer's misuse of equipment (e.g. wheelchair or hoist) 3 (0.6%); walking/banging into furniture 6 (1.2%); choking 1 (0.2%); and unknown causes 6 (1.2%).

Table 4.10. Causes of Injury Experienced at Least Once in a 12-Month Period by Adults with Learning Disabilities

SHS 2003 Categories	Whole Cohort N = 511 (100%)
Fall, trip or slip	62 (12.1%)
Hit by a falling object	1 (0.2%)
Road traffic accident	3 (0.6%)
Sports/recreational accident	7 (1.4%)
Use of a tool, implement or equipment	0 (0%)
Burn or scald	10 (2.0%)
Animal/insect bite or sting	1 (0.2%)
Another person (e.g. attacks)	5 (1.0%)
Lifting	0 (0%)
Other causes:	18 (3.5%)

4.2.3. Injuries Experienced by Older Adults with Learning Disabilities

Forty-one (8.0%) of the adults with learning disabilities in the whole cohort were aged 65 years or older. Of these older adults with learning disabilities, 9 (21.9%) had experienced at least one injury that required medical or nursing attention or treatment in the 12-month period. This compared with 96 (20.4%) in the adults with learning disabilities aged 18-64 years, hence there is no difference in rates between these different age groups. Of the older adults, 6 had been caused by falls/trips or slips, 3 had been caused by a road traffic accident (as a passenger or as a pedestrian), and 1 had been caused by a burn or scald. One older adult with learning disabilities had been injured more than once. The types of injuries reported by these older adults with learning disabilities were as follows: bruising or pinching a part of the body (4 persons), swelling or tenderness to a part of the body (2), cut or graze to a part of the body (2), burn or scald (1), and losing consciousness (1). Five (12.2%) of the older adults with learning disabilities had experienced repeated falls (three or more, with or without injury) in the 12-month period.

4.2.4. Self-Injury of Adults with Learning Disabilities

Nine (1.8%) adults with learning disabilities experienced incidence of at least one self-injury that required medical or nursing attention/treatment in the 12-month period. Eighteen (3.5%) of the whole cohort were known to have self-injurious behaviour

according to 'the Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities/Mental Retardation' (DC-LD) (Royal College of Psychiatrists, 2001).

4.2.4.1. Attempted Suicide

A further 3 (0.6%) adults with learning disabilities reported that they had required medical or nursing attention/treatment for a suicide attempt in the 12-month period: two instances of cuts to their wrists, and one instance of an attempted drug overdose.

4.2.5. Injury from Another Person (Harm)

Five (0.9%) adults with learning disabilities experienced an intentional (harmful) injury from another person that required medical or nursing attention or treatment in the 12-month period: two were harmed by another person without learning disabilities when they were out and about in their local community; two were harmed by another person with learning disabilities at their day centre; and one was harmed at home by a visiting relative (sibling).

4.2.5.1. Exposure to Challenging Behaviour of Others

Fifty-four (10.6%) of the adults with learning disabilities live with someone who has challenging/problem behaviour. The characteristics (gender, level of learning disabilities, and accommodation type) of these adults with learning disabilities, who live with someone who has challenging behaviour, are reported in *table 4.11*. Those who live with paid support were most likely to live with someone who has challenging behaviour.

Table 4.11. The Adults with Learning Disabilities Who Live with Someone Who Has Challenging Behaviour

	Whole Cohort **N = 511 (100%)**	**Adults who live with someone who has challenging behaviour** **N = 54 (100%)**
Gender:		
Male	273 (53.4%)	31 (57.4%)
Female	238 (46.6%)	23 (42.6%)
Level of LDs:		
Mild	201 (39.3%)	8 (14.8%)
Moderate	117 (22.9%)	18 (33.3%)
Severe	10 (19.0%)	10 (18.5%)
Profound	18 (18.8%)	18 (33.3%)
Accommodation type:		
Lives with paid support	230 (45.0%)	37 (68.5%)
Lives with family	218 (42.7%)	10 (18.5%)
Lives independently	44 (8.6%)	0 (0%)
Lives in congregate care	19 (3.2%)	7 (13.0%)

Seventy-four (14.5%) of the adults with learning disabilities come into contact with someone who has challenging behaviour somewhere else, out with their home. Their responses are reported in *table 4.12*.

Table 4.12. The Adults with Learning Disabilities who Came into Contact with Someone Who Has Challenging Behaviour Somewhere Else, Out With Their Home, and Where

Contact with someone who has challenging behaviour somewhere else, out with home	**Whole cohort N = 511 (100%)**
Yes:	74 (14.5%)
At day centre	*63 (12.3%)*
Youths (without LDs) in local area	*4 (0.8%)*
At another supported group home	*3 (0.6%)*
Did not specify where	*3 (0.6%)*
Visiting relative	*1 (0.2%)*
At respite unit	*1 (0.2%)*
No	412 (80.6%)
Did not know/refused to answer	25 (4.9%)

4.2.6. Where Adults with Learning Disabilities Became Injured

Where the 113 adults with learning disabilities became injured on 140 separate occasions are reported in *table 4.13*. Over half of all incidences of injury occurred at home, and the adults with learning disabilities were more likely to have become injured outdoors when they were on their own, unsupported by a carer.

Table 4.13. Where Persons with Learning Disabilities Became Injured

Location of Injury Incident	**Proportion of all incidences of injury reported N = 140 (100%)***
At home	75 (53.6%)
Outdoors:	47 (33.6%)
Supported by a carer	*18 (12.8%)*
Unsupported by a carer	*29 (20.7%)*
At work or day centre	12 (8.6%)
At respite centre	1 (0.7%)
At hospital	1 (0.7%)
Did not know where he/she became injured	4 (2.9%)

The location of injury incident information for the general population is only reported in the SHS 2003 (Scottish Executive, 2005) for each respondents' most recent incident, and therefore, is not directly comparable with this more detailed information on the location of injury incident information for all incidents experienced by adults with learning disabilities and their carers in this research project. This is why the location of injury data for the adults with learning disabilities is being reported here, in this section.

4.2.7. Section Summary

The results in this section have reported the different types and causes of injuries experienced by the whole cohort of adults with learning disabilities over a 12-month period. The frequency, types and causes of injury experienced by the older adults with learning disabilities within the sample were also described separately because these older adults are not included in the next section's comparison with general population data. The results presented in this section answer research question 2, 'What are the types of unintentional and intentional injuries and falls experienced by adults with learning disabilities over a 12-month period? '.

The commonest types of injuries experienced by the adults with learning disabilities were cuts and grazes (38 persons, 7.4%), bruising or pinching a part of the body (26 persons, 5.1%), swelling or tenderness (19 persons, 3.7%), and broken bones (16 persons, 3.1%). Falls were the commonest cause of injury (62 persons, 12.1%) followed by other causes not relevant for the general population (18 persons, 3.5%). These other causes of injury, which suggest that adults with learning disabilities experience a different pattern of injury causes than the general population, are explored further in the next section.

4.3. The Incidence, Types and Causes of Injury Compared with the General Population

4.3.1. Incidence of Injury Compared with the General Population

SHS 2003 (Scottish Government, 2005) provides general population injury data (excluding self-injury). The types and causes of injury experienced by adults in the SHS 2003 general population are included in the appendix (*appendix* 10). For the 6, 014 adults aged 18 – 64 years in the SHS 2003 the incidence of injury was 11.5% (692 people).

For the 936 adults aged 18 – 64 years in the SHS 2003 Greater Glasgow region sub-sample, the incidence of injury was 12.5% (117 people). Hence we would expect 59 out of

our cohort in the same region aged 18 – 64 years to have had incident injury. For adults with learning disabilities aged 18 to 64 years, the incidence of at least one injury excluding self-injury was actually 20.4% (96 adults out of 470 in this age group). Hence the standardized incident injury ratio was 1.63 (95% confidence interval (CI) = 1.55 – 1.71).

4.3.2. Types of Injury Compared with the General Population

The types of injury experienced at least once in the 12-month period by adults with learning disabilities aged 18 - 64 years compared with the same for adults aged 18 - 64 years in the SHS 2003 Greater Glasgow region general population sample are reported in *table 4.14*. Adults with learning disabilities were significantly more likely to have cuts/grazes, and significantly less likely to have straining or twisting injuries.

The 1 (0.2%) reported type of 'other' injury for the adults with learning disabilities was near drowning. The 1 (0.1%) reported type of 'other' injury for the regional general population was not stated/unknown.

Table 4.14. Types of Injury Experienced at Least Once in a 12-Month Period by Adults with Learning Disabilities and the General Population in Greater Glasgow, All Aged 18 – 64 Years

SHS 2003 Categories	**Adults with Learning Disabilities, N = 470**	**Greater Glasgow General Population N = 936**	χ^2	**P-value**
Broken bones	16 (3.4%)	18 (2.0%)	2.102	P = 0.147
Dislocated joints	3 (0.6%)	3 (0.3%)	0.569	P = 0.451
Losing consciousness	6 (1.3%)	8 (0.9%)	0.352	P = 0.553
Straining/twisting part of body	7 (1.5%)	41 (4.4%)	9.341	P = 0.002
Cutting or grazing part of body	36 (7.7%)	34 (3.6%)	8.362	P = 0.004
Bruising/pinching part of body	22 (4.7%)	34 (3.6%)	0.402	P = 0.526
Object stuck in part of body e.g. ear	1 (0.2%)	4 (4.4%)	0.515	P = 0.473
Burning or scalding	9 (1.9%)	8 (0.9%)	2.340	P = 0.126
Poisoning	4 (0.9%)	4 (4.4%)	0.759	P = 0.383
Internal injury	0 (0%)	6 (0.6%)	3.289	P = 0.070
Animal/insect bite or sting	1 (0.2%)	1 (0.1%)	0.189	P = 0.664
Swelling/tenderness part of body	17 (3.6%)	46 (4.9%)	2.001	P = 0.157
Other	1 (0.2%)	1 (0.1%)	0.189	P = 0.644

4.3.3. Causes of Injury Compared with the General Population

The causes of injury experienced at least once in the 12-month period by adults with learning disabilities aged 18 - 64 years compared with the same for adults aged 18 - 64 years in the SHS 2003 Greater Glasgow region sample are reported in *table 4.15.* 'Other' causes of injury experienced by 16 adults with learning disabilities aged 18 - 64 years were: poisoning (e.g. drug administration error) 3 (0.6%); carer's misuse of equipment (e.g. wheelchair or hoist) 3 (0.6%); walking/banging into furniture 5 (1.1%); choking 1 (0.2%); and unknown causes 4 (0.8%). Adults with learning disabilities were significantly more likely to experience injury from falls/trips/slips, and other causes, and significantly less likely to experience injury from use of a tool/implement/equipment.

The episode of 'near drowning' reported in the 'other' category in the previous section was caused by the brakes on the person's wheelchair not being properly secured by his support staff on a canal path. This serves as an example of 'carer's misuse of equipment' as a cause of injury.

Burns/scalds from using electrical appliances, such as a kettle or iron, were categorized correctly under 'burns/scalds' and not 'use of a tool, implement or equipment'.

Table 4.15. Causes of Injury Experienced at Least Once in a 12-Month Period by Adults with Learning Disabilities and Adults in the General Population in Greater Glasgow, All Aged 18 – 64 Years

SHS 2003 Categories	**Adults with Learning Disabilities, N = 470**	**Greater Glasgow general population sample N = 936**	χ^2	**P-value**
Fall, trip or slip	58 (12.3%)	44 (4.7%)	22.306	P < 0.001
Hit by a falling object	1 (0.2%)	7 (0.7%)	1.833	P = 0.176
Road traffic accident	3 (0.6%)	5 (0.5%)	0.017	P = 0.897
Sports or recreational accident	7 (1.5%)	22 (2.4%)	1.618	P = 0.203
Use of a tool/ implement/equipment	0 (0%)	9 (1.0%)	4.944	P = 0.026
Burn or scald	9 (1.9%)	7 (0.7%)	0.675	P = 0.411
Animal/insect bite or sting	1 (0.2%)	1 (0.1%)	0.189	P = 0.664
Another person (e.g. attacks)	5 (1.1%)	6 (0.6%)	0.499	P = 0.480
Lifting	0 (0%)	4 (0.4%)	2.190	P = 0.139
Other	16 (3.4%)	0 (0%)	27.736	P < 0.001

4.3.4. Section Summary

The results in this section, which have compared the incidence, types and causes of injuries experienced by the adults with learning disabilities with the same for the Greater Glasgow general population, has enabled a standardized incident injury ratio of 1.63 (95% CI = 1.55 – 1.71) to be calculated for the adults with learning disabilities (aged 18 – 64 years. The higher incidence and different pattern of types and causes of injuries experienced by the adults with learning disabilities, when compared with the regional general population of adults, answers research question 3, 'Are adults with learning disabilities more prone to injuries, accidents and falls, when compared with published general population data?' It also provides more data to answer research question 2, on the types and causes of unintentional and intentional injuries for the 18-64 year age group. Adults with learning disabilities are significantly more likely to experience injuries, and injuries from falls, when compared with the general population, as well as injuries from other causes not relevant for the general population.

4.4. Risk Factors for Injuries, Falls and Other Accidents

In all the following tables reporting results from the regression analyses, the results from the backward stepwise regression is reported. This is because comparison of the backward and stepwise analyses essentially showed no differences, with the same variables being retained in the models in each case.

4.4.1. Risk Factors for Incident Injury

Twenty-two T1 variables were investigated to determine whether they individually predicted incidence of at least one injury that required medical or nursing attention/treatment in the 12-month period (*table 4.16*). Percentages for the whole cohort are presented to indicate prevalence of these characteristics at Time 1, followed by percentages to indicate prevalence of incident injury. For example, 46 (20.3%) of the 227 in the whole cohort who have a visual impairment experienced at least one injury in the 12-month period.

A relationship with incident injury was found for urinary incontinence, epilepsy, not having Down syndrome, and number of prescribed drugs taken. Accommodation type and not having autism were of borderline significance. These therefore were the variables selected to investigate in the stage 2 binary logistic regression, to identify the factors independently predictive of incident injury.

Table 4.16. Relationship Between T1 Factors and Incident Injury (3 pages)

		Whole Cohort N = 511 (100%)	**Incident Injury N = 105 (20.5%)**	**χ^2/t-test**	**P-value**
Personal Factors					
Age	Incident cases Non-incident cases	Mean (SD)	44.6 (14.3) 43.5 (14.2)	0.729	P = 0.466
Gender	Male Female	273 (53.4%) 238 (46.6%)	59 (21.6%) 46 (19.3%)	0.406	P = 0.524
Ability Level	Mild Moderate Severe Profound	201 (39.3%) 117 (22.9%) 97 (19.0%) 96 (18.8%)	49 (24.4%) 22 (18.8%) 15 (15.5%) 22 (22.9%)	2.910	P = 0.406
Lifestyle/Supports					
Lives With	Family Carer Independently Paid Support Congregate Care	218 (42.7%) 44 (8.6%) 230 (45.0%) 19 (3.2%)	37 (17.0%) 15 (34.1%) 48 (20.9%) 5 (26.3%)	7.052	P = 0.070
No Job	Has Job No Job	123 (24.1%) 387 (75.9%)	29 (23.6%) 76 (19.6%)	0.886	P = 0.347

Area Deprivation	1 Most Affluent 2 3 4 5 Most Deprived	50 (9.8%) 25 (4.9%) 45 (8.8%) 67 (13.1%) 324 (63.4%)	6 (12.0%) 5 (20.0%) 8 (17.8%) 11 (16.4%) 75 (23.1%)	4.496	P = 0.343
Smoker	No Yes	452 (88.5%) 57 (11.2%)	94 (20.8%) 11 (19.3%)	0.069	P = 0.792
No. Life Events	Incident Cases Non-incident cases	Mean (SD)	1.2 (1.6) 1.0 (1.5)	1.306	P = 0.192
Health					
Visual impairment	No Yes	284 (55.6%) 227 (44.4%)	59 (20.8%) 46 (20.3%)	0.020	P = 0.887
Hearing impaired	No Yes	371 (72.6%) 140 (27.4%)	80 (21.6%) 25 (17.9%)	0.855	P = 0.355
Bowel incontinence	No Yes	392 (76.7%) 118 (23.1%)	81 (20.7%) 24 (20.3%)	0.006	P = 0.939
Urine incontinence	No Yes	344 (67.5%) 166 (32.5%)	62 (18.0%) 43 (25.9%)	4.253	P = 0.039
Impaired mobility	No Yes	395 (77.5%) 115 (22.5%)	79 (20.0%) 26 (22.6%)	0.371	P = 0.543
Foot/toe deformity	No Yes	386 (67.6%) 125 (24.5%)	83 (21.5) 22 (17.6)	0.881	P = 0.348

Epilepsy	No Yes	338 (67.6%) 162 (32.4%)	59 (17.5%) 45 (27.7%)	7.083	P = 0.008
Body Mass Index	Underweight Acceptable weight Overweight Obese Morbidly obese	30 (5.9%) 157 (30.7%) 157 (30.7%) 131 (25.6%) 36 (7.0%)	4 38 29 21 10	9.896	P = 0.420
Special needs in communication	No Yes	265 (52.5%) 240 (47.5%)	52 (19.6%) 52 (21.7%)	0.322	P = 0.571
Down Syndrome	No Yes	402 (78.7%) 109 (21.3%)	90 (22.4%) 15 (13.8%)	3.909	P = 0.048
Autism	No Yes	485 (94.9%) 26 (5.1%)	103 (21.2%) 2 (7.7%)	2.773	P = 0.096
Problem behaviour	No Yes	425 (83.2%) 86 (16.8%)	83 (19.5%) 22 (25.6%)	1.605	P = 0.205
Mental ill-health	No Yes	402 (78.7%) 109 (21.3%)	78 (19.4%) 27 (24.8%)	1.513	P = 0.219
Number of Drugs (> 3 drugs)	No Yes	450 (88.1%) 61 (11.9%)	92 (87.6%) 13 (12.4%)	2.403	P = 0.872

4.4.1.1. T1 Factors for Incident Injury

The T1 variables with P-values less than 0.1 were entered into the backward stepwise regression for incident injury: epilepsy; Down syndrome; autism; urinary incontinence; and accommodation type. Having epilepsy was found to be independently predictive of incident injury, and autism was found to be a protective factor (*table 4.17.*).

Table 4.17. T1 Factors Independently Predictive of Incident Injury

	Odds Ratio	**95% Confidence Interval**	**Change in -2 Log Likelihood**	**P**
Epilepsy	1.809	1.158 – 2.2826	6.666	0.010
Down syndrome	-	-	-	-
Autism	0.153	0.020 – 1.140	5.978	0.014
Urine incontinence	-	-	-	-
Accommodation	-	-	-	-

4.4.1.2. T2 Factors for Incident Injury

Nine T2 variables were investigated to determine whether they were associated with incidence of at least one injury that required medical or nursing attention or treatment in the 12-month period (*table 4.18*). Physical activity level data was categorised using SHS 2003 summary physical activity level categories (Finlayson et al., 2009). Poorly fitting shoes were identified by comparing actual measured shoe size with size of shoes worn.

Table 4.18. Relationship between Individual T2 Factors and Incident Injury

		Whole Cohort N = 511 (100%)	**Incident Injury N = 105 (20.5%)**	χ^2	**P-value**
Disabilities					
Poor balance/coordination	No Yes	289 (58.3%) 213 (41.7%)	52 (17.4%) 53 (24.9%)	4.204	P = 0.040
Restless/impatient	No Yes	305 (59.7%) 206 (40.3%)	59 (19.3%) 46 (22.3%)	0.671	P = 0.413
Clumsy/accident prone	No Yes	332 (25.6%) 114 (74.4%)	58 (17.5%) 29 (25.4%)	3.432	P = 0.064
Carer's Opinions					
Most accidents are preventable	No Yes	156 (35.0%) 290 (65.0%)	35 (22.4%) 52 (17.9%)	1.311	P = 0.252
Participant has a fear of falling	No Yes	297 (66.6%) 149 (33.4%)	58 (19.5%) 29 (19.5%)	0.000	P = 0.987
Activities					
Uses public transport	No Yes	301 (58.9%) 210 (41.1%)	61 (20.3%) 44 (21.0%)	0.036	P = 0.850
Physical activity level	Active Inactive	367 (71.8%) 144 (28.2%)	71 (19.3%) 34 (23.6%)	1.152	P = 0.283
Injury related to season/weather	No Yes	405 (90.8%) 41 (9.2%)	75 (18.5%) 12 (29.3%)	2.740	P = 0.098
Poorly fitting shoes	No Yes	460 (90.0%) 51 (10.0%)	91 (19.8%) 14 (27.5%)	1.654	P = 0.198

Three T2 factors with P-values less than 0.1 were entered into the backward stepwise regression: poor balance/coordination; person being clumsy/accident prone; and person's injury being related to season/weather. However, in the regression, none of these were found to be independently related to incident injury.

The same two-step procedure for T1 and then T2 regressions was then repeated to identify risk factors for: incident fall injury (including epilepsy-related falls); incident fall injury (excluding epilepsy-related falls); repeated falls with or without injury (≥ 3 falls); and

incident accidental injury (other than falls). These results are reported over the following sections. There were no missing values for any of the T1 (n = 511) and T2 (n = 446) regressions.

4.4.2. Risk Factors for Incident Fall Injury (Including Epilepsy-Related)

Table 4.19 reports the findings for individual associations between the 22 T1 variables of interest, and the dependant variable, incident fall injury (including epilepsy-related falls). Four of the T1 variables investigated had P-values less than 0.1: urinary incontinence; epilepsy; not having Down syndrome; and number of prescribed drugs. These were therefore investigated further in the second stage regression. No persons with autism had experienced at least one incident of fall injury, including epilepsy-related falls, and so autism was not investigated further.

Table 4.19. Relationship Between T1 Factors and Incident Fall Injury (Including Epilepsy-Related) (3 pages)

		Whole Cohort N = 511 (100%)	**Incident Fall Injury N = 62 (12.1%)**	**χ^2/t-test**	**P-value**
Personal Factors					
Age	Incident cases Non-incident cases	Mean (SD)	46 (13.9) 43 (14.2)	1.409	P = 0.159
Gender	Male Female	273 (53.4%) 238 (46.6%)	32 (11.7%) 30 (12.6%)	0.093	P = 0.760
Ability Level	Mild Moderate Severe Profound	201 (39.3%) 117 (22.9%) 97 (19.0%) 96 (18.8%)	29 (14.4%) 11 (9.4%) 12 (12.4%) 10 (10.4%)	1.969	P = 0.579
Lifestyle/Supports					
Lives With	Family Carer Independently Paid Support Congregate Care	218 (42.7%) 44 (8.6%) 230 (45.0%) 19 (3.2%)	21 (9.6%) 9 (20.5%) 29 (12.6%) 3 (15.8%)	4.423	P = 0.219
No Job	Has Job No Job	123 (24.1%) 387 (75.9%)	17 (13.8%) 45 (11.6%)	0.420	P = 0.517

Area Deprivation	1 Most Affluent 2 3 4 5 Most Deprived	50 (9.8%) 25 (4.9%) 45 (8.8%) 67 (13.1%) 324 (63.4%)	4 (8.0%) 2 (8.0%) 7 (15.6%) 7 (10.4%) 42 (13.0%)	2.084	P = 0.720
Smoker	No Yes	452 (88.5%) 57 (11.2%)	55 (12.2%) 7 (12.3%)	0.001	P = 0.987
No. Life Events	Incident Cases Non-incident cases	Mean (SD)	1 (1.5) 1 (1.5)	0.442	P = 0.658
Health					
Visual impairment	No Yes	284 (55.6%) 227 (44.4%)	37 (13.0%) 25 (11.0%)	0.480	P = 0.488
Hearing impaired	No Yes	371 (72.6%) 140 (27.4%)	48 (12.9%) 14 (10.0%)	0.823	P = 0.364
Bowel incontinence	No Yes	392 (76.7%) 118 (23.1%)	46 (11.7%) 16 (13.6%)	0.283	P = 0.595
Urine incontinence	No Yes	344 (67.5%) 166 (32.5%)	33 (9.6%) 29 (17.5%)	6.505	P =0.011
Impaired mobility	No Yes	395 (77.5%) 115 (22.5%)	46 (11.6%) 16 (13.9%)	0.429	P = 0.513
Foot/toe deformity	No Yes	386 (67.6%) 125 (24.5%)	49 (12.7%) 13 (10.4%)	0.466	P = 0.495

Epilepsy	No Yes	338 (67.6%) 162 (32.4%)	30 (8.9%) 32 (19.8%)	11.928	P = 0.001
Body mass index	Underweight Acceptable weight Overweight Obese Morbidly obese	30 (5.9%) 157 (30.7%) 157 (30.7%) 131 (25.6%) 36 (7.0%)	3 (10%) 22 (14.0%) 17 (10.8%) 12 (9.16%) 6 (16.6%)	4.835	P = 0.305
Special needs in communication	No Yes	265 (52.5%) 240 (47.5%)	30 (11.3%) 31 (12.9%)	0.302	P = 0.583
Down Syndrome	No Yes	402 (78.7%) 109 (21.3%)	56 (13.9%) 6 (5.5%)	5.710	P = 0.017
Autism	No Yes	485 (94.9%) 26 (5.1%)	62 (12.8%) 0 (0%)	*3.783	P = 0.059
Problem behaviour	No Yes	425 (83.2%) 86 (16.8%)	48 (11.3%) 14 (16.3%)	1.667	P = 0.197
Mental ill-health	No Yes	402 (78.7%) 109 (21.3%)	46 (11.4%) 16 (14.7%)	0.842	P = 0.359
No. Drugs (> 3 drugs)	No Yes	450 (88.1%) 61 (11.9%)	52 (83.9%) 10 (16.1%)	2.082	P = 0.277

* Fisher's exact test

4.4.2.1. T1 Factors for Incident Fall Injury (Including Epilepsy-Related)

Of the three T1 variables entered into the regression, epilepsy was found to be independently predictive of incident fall injury, including epilepsy-related falls (*table 4.20*).

Table 4.20. T1 Factors Independently Predictive of Incident Fall Injury (Including Epilepsy-Related Falls)

	Odds Ratio	**95% Confidence Interval**	**Change in -2 Log Likelihood**	**P**
Epilepsy	2.527	1.475 – 4.331	11.239	0.005
Down syndrome	-	-	-	-
Urine incontinence	-	-	-	-

4.4.2.2. T2 Factors for Incident Fall Injury (Including Epilepsy-Related)

The T2 variables investigated to determine whether they were individually associated with incidence of at least one fall injury, including epilepsy-related falls, that required medical or nursing attention/treatment in the 12-month period with P-values less than 0.1 were being clumsy/accident prone, poor balance/coordination, and injury related to season/weather. The results for all the investigated T2 variables are shown in *table 4.21* These three results which were individually significantly related were then further in the T2 logistic regression.

Table 4.21. Relationship Between Individual T2 Factors and Incident Fall Injury (Including Epilepsy-Related Falls)

		Whole Cohort N = 511 (100%)	**Incident Fall Injury N = 62 (12.1%)**	χ^2	**P-value**
Disabilities					
Poor balance/coordination	No Yes	289 (58.3%) 213 (41.7%)	28 (9.4%) 34 (16.0%)	5.024	P = 0.025
Restless/impatient	No Yes	305 (59.7%) 206 (40.3%)	33 (10.8%) 29 (14.1%)	1.224	P = 0.269
Clumsy/accident prone	No Yes	332 (25.6%) 114 (74.4%)	29 (8.7%) 33 (10.8%)	7.999	P = 0.005
Carer's Opinions					
Most accidents are preventable	No Yes	156 (35.0%) 290 (65.0%)	15 (9.6%) 35 (12.1%)	0.613	P = 0.433
Participant has a fear of falling	No Yes	297 (66.6%) 149 (33.4%)	31 (10.4%) 19 (12.8%)	0.534	P = 0.465
Activities					
Uses public transport	No Yes	301 (58.9%) 210 (41.1%)	36 (12.0%) 26 (12.4%)	0.021	P = 0.886
Physical activity	Inactive Active	367 (71.8%) 144 (28.2%)	44 (12.0%) 18 (12.5%)	0.025	P = 0.874)
Injury related to season/weather	No Yes	405 (90.8%) 41 (9.2%)	40 (9.9%) 10 (24.4%)	7.879	P = 0.005
Poorly fitting shoes	No Yes	460 (90.0%) 51 (10.0%)	56 (12.2%) 6 (11.8%)	0.007	P = 0.932

In the second stage regression, being clumsy/accident prone and injury related to season/weather were found to be independently related to incident fall injury, including epilepsy-related falls (*table 4.22*).

Table 4.22. T2 Factors Independently Related to Incident Fall Injury (Including Epilepsy-Related Falls)

	Odds Ratio	**95% Confidence Interval**	**Change in -2 Log Likelihood**	**P**
Poor balance/coordination	-	-	-	-
Clumsy/accident prone	2.205	1.191 – 4.082	6.045	0.014
Injury related to season/weather	2.648	1.193 – 5.879	5.082	0.024

4.4.3. Risk Factors for Incident Fall Injury (Excluding Epilepsy-Related)

The T1 variables were then investigated to determine whether they predicted incidence of at least one fall injury that required medical or nursing attention/treatment in the 12-month period, this time with injury from epilepsy-related falls excluded (*table 4.23*). Age, urinary incontinence, epilepsy, and *not* having Down syndrome were individually related, and type of accommodation and number of prescribed drugs were of borderline individually related. These were the variables entered into the second stage regression. No persons with autism had experienced at least one incident fall injury.

Table 4.23. Relationship Between T1 Factors and Incident Fall Injury (Epilepsy-Related Falls Excluded) (3 pages)

		Whole Cohort **N = 511** **(100%)**	**Incident Non-Epilepsy Fall Injury** **N = 52** **(10.4%)**	**χ^2/t-test**	**P-value**
Personal Factors					
Age	Incident cases Non-incident cases	Mean (SD)	48 (13.1) 43 (14.2)	0.927	P = 0.046
Gender	Male Female	273 (53.4%) 238 (46.6%)	25 (9.2%) 27 (11.3%)	0.665	P = 0.444
Ability Level	Mild Moderate Severe Profound	201 (39.3%) 117 (22.9%) 97 (19.0%) 96 (18.8%)	25 (12.4%) 8 (6.8%) 10 (10.3%) 9 (9.4%)	2.497	P = 0.480
Lifestyle/Supports					
Lives With	Family Carer Independently Paid Support Congregate Care	218 (42.7%) 44 (8.6%) 230 (45.0%) 19 (3.2%)	15 (6.9%) 8 (18.2%) 26 (11.3%) 3 (15.8%)	6.650	P = 0.090
No Job	Has Job No Job	123 (24.1%) 387 (75.9%)	16 (13.0%) 36 (9.3%)	1.400	P = 0.259

Area Deprivation	1 Most Affluent 2 3 4 5 Most Deprived	50 (9.8%) 25 (4.9%) 45 (8.8%) 67 (13.1%) 324 (63.4%)	3 (6.0%) 2 (8.0%) 7 (15.6%) 5 (7.5%) 35 (10.8%)	3.187	P = 0.548
Smoker	No Yes	452 (88.5%) 57 (11.2%)	45 (10.0%) 7 (12.3%)	0.298	P = 0.625
No. Life Events	Incident Cases Non-incident cases	Mean (SD)	1 (1.7) 1 (1.5)	1.429	P = 0.337
Health					
Visual impairment	No Yes	284 (55.6%) 227 (44.4%)	32 (11.3%) 20 (8.8%)	0.833	P = 0.370
Hearing impaired	No Yes	371 (72.6%) 140 (27.4%)	41 (11.1%) 11 (7.9%)	1.134	P = 0.290
Bowel incontinence	No Yes	392 (76.7%) 118 (23.1%)	37 (9.4%) 15 (12.7%)	1.061	P = 0.327
Urine incontinence	No Yes	344 (67.5%) 166 (32.5%)	27 (7.8%) 25 (15.1%)	6.359	P = 0.011
Impaired mobility	No Yes	395 (77.5%) 115 (22.5%)	38 (9.6%) 14 (12.2%)	0.634	P = 0.431
Foot/toe deformity	No Yes	386 (67.6%) 125 (24.5%)	39 (10.1%) 13 (10.4%)	0.009	P = 0.993

Epilepsy	No Yes	338 (67.6%) 162 (32.4%)	29 (8.6%) 23 (14.2%)	6.722	P = 0.032
Body mass index	Underweight Acceptable weight Overweight Obese Morbidly obese	30 (5.9%) 157 (30.7%) 157 (30.7%) 131 (25.6%) 36 (7.0%)	2 (6.7%) 17 (10.8%) 17 (10.8%) 9 (6.9%) 5 (13.9%)	3.721	P = 0.445
Special needs in communication	No Yes	265 (52.5%) 240 (47.5%)	23 (8.7%) 29 (14.2%)	1.580	P = 0.235
Down Syndrome	No Yes	402 (78.7%) 109 (21.3%)	47 (11.7%) 5 (4.6%)	4.735	P = 0.027
Autism	No Yes	485 (94.9%) 26 (5.1%)	52 (10.7%) 0 (0%)	*3.103	P = 0.096
Problem behaviour	No Yes	425 (83.2%) 86 (16.8%)	39 (9.2%) 13 (15.1%)	2.761	P = 0.103
Mental ill-health	No Yes	402 (78.7%) 109 (21.3%)	37 (9.2%) 15 (13.8%)	1.949	P = 0.177
No. Drugs (> 3 drugs)	No Yes	450 (88.1%) 61 (11.9%)	46 (88.4%) 6 (11.6%)	0.096	P = 0.925

* Fisher's exact test

4.4.3.1. T1 Factors for Incident Fall Injury (Excluding Epilepsy-Related)

Five T1 variables were entered into the regression: age; epilepsy; Down syndrome; urinary incontinence; and accommodation type. Of these, urinary incontinence was found to be independently predictive of incident fall injury, excluding epilepsy-related falls, and Down syndrome was found to be independently protective (*table 4.24*).

Table 4.24. T1 Factors Independently Predictive of Incident Fall Injury (Excluding Epilepsy-Related Falls)

	Odds Ratio	**95% Confidence Interval**	**Change in -2 Log Likelihood**	**P**
Age	-	-	-	-
Epilepsy	-	-	-	-
Down syndrome	0.416	0.160 – 1.086	3.890	0.049
Urine incontinence	1.976	1.098 – 3.556	5.067	0.024
Accommodation	-	-	-	-

4.4.3.2. T2 Factors for Incident Fall Injury (Excluding Epilepsy-Related)

The T2 variables investigated to determine whether they were individually associated with incidence of at least one fall injury excluding epilepsy-related falls that required medical or nursing attention/treatment in the 12-month period with P-values less than 0.1 (i.e. significant or of borderline significance) were then entered into the stage 2 regression. They were being clumsy/accident prone, poor balance/coordination, injury related to season/weather, and a fear of falling (*table 4.25*).

Table 4.25. Relationship Between Individual T2 Factors and Incident Fall Injury (Excluding Epilepsy-Related Falls)

		Whole Cohort N = 511 (100%)	**Incident Injury N = 52 (10.4%)**	χ^2	**P-value**
Disabilities					
Poor balance/coordination	No Yes	289 (58.3%) 213 (41.7%)	24 (8.1%) 34 (16.0%)	3.523	P = 0.061
Restless/impatient	No Yes	305 (59.7%) 206 (40.3%)	28 (9.2%) 24 (11.7%)	0.821	P = 0.365
Clumsy/accident prone	No Yes	332 (25.6%) 114 (74.4%)	23 (6.9%) 18 (15.8%)	7.983	P = 0.005
Carer's Opinions					
Most accidents are preventable	No Yes	156 (35.0%) 290 (65.0%)	29 (18.6%) 12 (4.1%)	0.647	P = 0.421
Participant has a fear of falling	No Yes	297 (66.6%) 149 (33.4%)	22 (7.4%) 19 (12.8%)	3.395	P = 0.065
Activities					
Uses public transport	No Yes	301 (58.9%) 210 (41.1%)	30 (10.10%) 22 (10.5%)	0.035	P = 0.851
Physical activity level	Active Inactive	367 (71.8%) 144 (28.2%)	38 (10.4%) 14 (9.7%)	0.045	P = 0.832
Injury related to season/weather	No Yes	405 (90.8%) 41 (9.2%)	31 (7.7%) 10 (24.4%)	12.492	P < 0.001
Poorly fitting shoes	No Yes	460 (90.0%) 51 (10.0%)	46 (10.0%) 6 (11.8%)	0.156	P = 0.692

In the regression analysis, being clumsy/accident prone and injury related to season/weather were found to be independently related to incident fall injury, excluding epilepsy-related falls (*table 4.26*).

Table 4.26. T2 Factors Independently Related to Incident Fall Injury (Excluding Epilepsy-Related Falls)

	Odds Ratio	**95% Confidence Interval**	**Change in -2 Log Likelihood**	**P**
Poor balance/coordination	-	-	-	-
Clumsy/accident prone	2.329	1.190 – 4.559	5.813	0.016
Injury related to season/weather	3.401	1.503 – 7.694	7.512	0.006
Fear of falling	-	-	-	-

4.4.4. Risk Factors for Repeated Falls With or Without Injury

T1 variables were investigated to determine whether they were predictive of repeated falls (≥ 3 falls) with or without injury in the 12-month period (*table 4.27*). Urinary incontinence and *not* having Down syndrome were significantly individually predictive, and impaired mobility was of borderline significance; these variables were therefore entered into the second stage regression.

Table 4.27. Relationship Between Time 1 Factors and Repeated Falls (≥ 3) With or Without Injury (3 pages)

		Whole Cohort N = 511 (100%)	**Repeated Falls N = 86 (16.8%)**	**χ^2/t-test**	**P-value**
Personal Factors					
Age	Incident cases	Mean (SD)	42.4 (14.5)	-0.916	P = 0.360
	Non-incident cases		43.9 (14.1)		
Gender	Male	273 (53.4%)	44 (16.2%)	0.213	P = 0.645
	Female	238 (46.6%)	42 (17.6%)		
Ability Level	Mild	201 (39.3%)	34 (16.9%)	7.572	P = 0.650
	Moderate	117 (22.9%)	27 (5.9%)		
	Severe	97 (19.0%)	9 (9.3%)		
	Profound	96 (18.8%)	16 (26.7%)		
Lifestyle/Supports					
Lives With	Family Carer	218 (42.7%)	39 (17.9%)	4.198	P = 0.241
	Independently	44 (8.6%)	8 (18.2%)		
	Paid Support	230 (45.0%)	33 (1.4%)		
	Congregate Care	19 (3.2%)	6 (6.7%)		
No Job	Has Job	123 (24.1%)	61 (49.6%)	1.386	P = 0.239
	No Job	387 (75.9%)	25 (6.4%)		
Area Deprivation	1 Most Affluent	50 (9.8%)	7 (14.0%)	5.255	P = 0.262
	2	25 (4.9%)	3 (12.0%)		
	3	45 (8.8%)	3 (6.7%)		
	4	67 (13.1%)	14 (20.9%)		

	5 Most Deprived	324 (63.4%)	59 (18.2%)		
Smoker	No Yes	452 (88.5%) 57 (11.2%)	72 (15.9%) 14 (24.6%)	0.492	P = 0.483
No. Life Events	Incident Cases Non-incident cases	Mean (SD)	0.9 (1.1) 1.1 (1.5)	-0.909	P = 0.364
Health					
Visual impairment	No Yes	284 (55.6%) 227 (44.4%)	48 (16.9%) 38 (16.7%)	0.002	P = 0.961
Hearing impaired	No Yes	371 (72.6%) 140 (27.4%)	60 (16.2%) 26 (18.6%)	0.418	P = 0.518
Bowel incontinence	No Yes	392 (76.7%) 118 (23.1%)	63 (16.1%) 23 (19.5%)	0.777	P = 0.378
Urine incontinence	No Yes	344 (67.5%) 166 (32.5%)	50 (14.5%) 36 (21.7%)	4.011	P = 0.042
Impaired mobility	No Yes	395 (77.5%) 115 (22.5%)	60 (15.2%) 26 (22.6%)	3.350	P = 0.060
Foot/toe deformity	No Yes	386 (67.6%) 125 (24.5%)	68 (18.9%) 18 (14.4%)	0.644	P = 0.422
Epilepsy	No Yes	338 (67.6%) 162 (32.4%)	58 (17.2%) 28 (17.5%)	2.599	0.107

Body mass index	Underweight Acceptable weight Overweight Obese Morbidly obese	30 (5.9%) 157 (30.7%) 157 (30.7%) 131 (25.6%) 36 (7.0%)	9 (30.0%) 23 (14.6%) 27 (17.2%) 18 (16.4%) 9 (25.0%)	1.179	P = 0.882
Special needs in communication	No Yes	265 (52.5%) 240 (47.5%)	41 (15.5%) 45 (18.8%)	1.192	P = 0.275
Down Syndrome	No Yes	402 (78.7%) 109 (21.3%)	78 (19.4%) 8 (7.3%)	10.379	P = 0.003
Autism	No Yes	485 (94.9%) 26 (5.1%)	84 (17.3%) 2 (7.7%)	1.634	P = 0.201
Problem behaviour	No Yes	425 (83.2%) 86 (16.8%)	68 (16.0%) 18 (20.9%)	1.242	P = 0.265
Mental ill-health	No Yes	402 (78.7%) 109 (21.3%)	49 (12.2%) 37 (33.9%)	1.511	P = 0.219
No. Drugs (> 3 drugs)	No Yes	450 (88.1%) 61 (11.9%)	78 (19.4%) 8 (7.3%)	0.863	P = 0.357

4.4.4.1. T1 Factors for Repeated Falls With or Without Injury

The T1 factors with P-values less than 0.1 that were entered into the regression were mobility problems, urinary incontinence, and Down syndrome. The latter two were found to be independently predictive factors (*table 4.28*).

Table 4.28. T1 Factors Independently Predictive of Repeated Falls (≥ 3) With or Without Injury

	Odds Ratio	**95% Confidence Interval**	**Change in -2 Log Likelihood**	**P**
Mobility problems	-	-	-	-
Urinary incontinence	1.810	1.053 – 3.111	4.538	0.032
Down syndrome	0.345	0.307 – 1.320	8.963	0.007

4.4.4.2. T2 Factors and Repeated Falls With or Without Injury

T2 variables were investigated to determine whether they were individually associated with incidence of repeated falls (≥ 3 falls) with or without injury in the 12-month period (*table 4.29*). Poor balance/coordination, being clumsy/accident-prone, not using public transport and having falls related to the season/weather were associated. These therefore were the variables that were then entered into the second stage regression.

Table 4.29. Relationship Between Individual T2 Factors and Repeated Falls (≥ 3) With or Without Injury

		Whole Cohort N = 511 (100%)	**Incident Injury N = 86 (16.8%)**	χ^2	**P-value**
Disabilities					
Poor balance/coordination	No Yes	289 (58.3%) 213 (41.7%)	32 (11.1%) 54 (25.3%)	18.952	P < 0.001
Restless/impatient	No Yes	305 (59.7%) 206 (40.3%)	47 (15.4%) 39 (18.9%)	1.090	P = 0.297
Clumsy/accident prone	No Yes	332 (25.6%) 114 (74.4%)	57 (17.2%) 29 (25.4%)	9.774	P = 0.002
Carer's Opinions					
Most accidents are preventable	No Yes	156 (35.0%) 290 (65.0%)	43 (27.6%) 43 (14.8%)	1.061	P = 0.303
Participant has a fear of falling	No Yes	297 (66.6%) 149 (33.4%)	59 (19.8%) 27 (18.1%)	0.646	P = 0.421
Activities					
Uses public transport	No Yes	301 (58.9%) 210 (41.1%)	60 (19.9%) 26 (12.4%)	5.041	P = 0.025
Physical activity level	Active Inactive	367 (71.8%) 144 (28.2%)	56 (15.2%) 30 (21.4%)	2.296	P = 0.130
Injury related to season/weather	No Yes	405 (90.8%) 41 (9.2%)	70 (17.3%) 16 (39.0%)	15.688	P < 0.001
Poorly fitting shoes	No Yes	460 (90.0%) 51 (10.0%)	80 (17.4%) 6 (11.8%)	1.032	P = 0.308

The regression with the four T2 variables (P less than 0.1) (*table 4.30*) determined that the following three were independently associated with repeated falls: weather/seasonal factor; being clumsy or accident prone; and having poor balance/coordination.

Table 4.30. T2 Factors Independently Related to Repeated Falls (≥ 3) With or Without Injury

	Odds Ratio	**95% Confidence Interval**	**Change in -2 Log Likelihood**	**P**
Uses public transport	-	-	-	-
Clumsy/accident prone	1.779	1018 – 3.109	3.972	0.043
Injury related to season/weather	0.001	1.605 – 6.652	9.842	0.001
Poor balance/coordination	2.228	1.290 – 3.847	8.434	0.004

4.4.5. Risk Factors for Incident Accidental Injury

T1 variables were tested for significance for incidence of at least one accidental injury, from accidents other than falls, which required medical or nursing attention/treatment in the 12-month period (*table 4.31*). None were found to be predictive at either a significant or a borderline significant level.

Table 4.31. Relationship Between Time 1 Factors and Incident Accidental Injury (Other than Falls) (3 pages)

		Whole Cohort **N = 511 (100%)**	**Incident Accidental Injury** **N = 43 (100%)**	**χ^2/t-test**	**P-value**
Personal Factors					
Age	Incident cases Non-incident cases	Mean (SD)	42 (15.4) 44 (14.1)	-0.593	P = 0.553
Gender	Male Female	273 (53.4%) 238 (46.6%)	28 (10.3%) 15 (6.3%)	2.579	P = 0.108
Ability Level	Mild Moderate Severe Profound	201 (39.3%) 117 (22.9%) 97 (19.0%) 96 (18.8%)	16 (8.0%) 11 (9.4%) 4 (4.1%) 12 (12.5%)	4.788	P = 0.188
Lifestyle/Supports					
Lives With	Family Carer Independently Paid Support Congregate Care	218 (42.7%) 44 (8.6%) 230 (45.0%) 19 (3.2%)	16 (7.3%) 7 (15.9%) 19 (8.3%) 1 (5.3%)	3.786	P = 0.286
No Job	Has Job No Job	123 (24.1%) 387 (75.9%)	12 (9.8%) 31 (8.0%)	0.368	P = 0.544

Area Deprivation	1 Most Affluent 2 3 4 5 Most Deprived	50 (9.8%) 25 (4.9%) 45 (8.8%) 67 (13.1%) 324 (63.4%)	3 (6.0%) 2 (8.0%) 7 (15.6%) 5 (7.5%) 35 (10.8%)	3.672	P = 0.452
Smoker	No Yes	452 (88.5%) 57 (11.2%)	39 (8.6%) 4 (7.0%)	0.170	P = 0.680
No. Life Events	Incident Cases Non-incident cases	Mean (SD)	1 (1.6) 1 (1.5)	1.055	P = 0.292
Health					
Visual impairment	No Yes	284 (55.6%) 227 (44.4%)	23 (8.1%) 20 (8.8%)	0.083	P = 0.773
Hearing impaired	No Yes	371 (72.6%) 140 (27.4%)	34 (9.2%) 9 (6.4%)	0.987	P = 0.320
Bowel incontinence	No Yes	392 (76.7%) 118 (23.1%)	35 (8.9%) 8 (6.8%)	0.542	P = 0.461
Urine incontinence	No Yes	344 (67.5%) 166 (32.5%)	31 (9.0%) 12 (7.2%)	0.461	P = 0.497
Impaired mobility	No Yes	395 (77.5%) 115 (22.5%)	32 (8.1%) 11 (9.6%)	0.247	P = 0.619
Foot/toe deformity	No Yes	386 (67.6%) 125 (24.5%)	36 (9.3%) 7 (5.6%)	1.701	P = 0.192

Epilepsy	No Yes	338 (67.6%) 162 (32.4%)	27 (8.0%) 15 (9.3%)	0.230	P = 0.632
Body mass index	Underweight Acceptable weight Overweight Obese Morbidly obese	30 (5.9%) 157 (30.7%) 157 (30.7%) 131 (25.6%) 36 (7.0%)	1 (3.3%) 17 (10.8%) 11 (7.0%) 9 (6.9%) 4 (11.1%)	5.619	P = 0.230
Special needs in communication	No Yes	265 (52.5%) 240 (47.5%)	22 (8.3%) 21 (8.3%)	0.000	P = 0.990
Down Syndrome	No Yes	402 (78.7%) 109 (21.3%)	8 (19.9%) 35 (32.1%)	0.208	P = 0.648
Autism	No Yes	485 (94.9%) 26 (5.1%)	41 (8.5%) 2 (7.7%)	0.019	P = 0.892
Problem behaviour	No Yes	425 (83.2%) 86 (16.8%)	35 (8.2%) 8 (9.3%)	0.106	P = 0.745
Mental ill-health	No Yes	402 (78.7%) 109 (21.3%)	33 (8.2%) 10 (9.2%)	0.104	P = 0.747
No. Drugs (> 3 drugs)	No Yes	450 (88.1%) 61 (11.9%)	41 (95.3%) 2 (4.7%)	2.465	P = 0.124

4.4.5.1. T1 Factors for Incident Accidental Injury

No T1 factors entered were found to be independently predictive of incident accidental injury (other than falls), hence they were not investigated any further.

4.4.5.2. T2 Factors for Incident Accidental Injury

The T2 variables investigated to determine whether they were associated with incidence of at least one accidental injury, from accidents other than falls, which required medical or nursing attention/treatment in the 12-month period are reported in *table 4.32*. The only significant finding was the carer's perception that most accidents are not preventable. A regression was therefore not required.

Table 4.32. Relationship Between Individual T2 Factors and Incident Accidental Injury (Other than Falls)

		Whole Cohort N = 511 (100%)	**Incident Injury N = 43 (8.4%)**	χ^2	**P-value**
Disabilities					
Poor balance/coordination	No Yes	289 (58.3%) 213 (41.7%)	25 (8.1%) 18 (8.5%)	0.001	P = 0.980
Restless/impatient	No Yes	305 (59.7%) 206 (40.3%)	25 (8.2%) 18 (8.7%)	0.047	P = 0.829
Clumsy/accident prone	No Yes	332 (25.6%) 114 (74.4%)	23 (6.9%) 18 (5.8%)	0.229	P = 0.632
Carer's Opinions					
Most accidents are preventable	No Yes	156 (35.0%) 290 (65.0%)	19 (12.2%) 17 (5.9%)	5.456	P = 0.020
Participant has a fear of falling	No Yes	297 (66.6%) 149 (33.4%)	25 (8.4%) 11 (7.4%)	0.143	P = 0.705
Activities					
Uses public transport	No Yes	301 (58.9%) 210 (41.1%)	24 (8.0%) 19 (9.0%)	0.185	P = 0.667
Physical activity level	Active Inactive	367 (71.8%) 144 (28.2%)	28 (7.6%) 15 (10.4%)	1.043	P = 0.307
Injury related to season/weather	No Yes	405 (90.8%) 41 (9.2%)	35 (8.6%) 1 (2.4%)	1.931	P = 0.165
Poorly fitting shoes	No Yes	460 (90.0%) 51 (10.0%)	37 (8.0%) 6 (11.8%)	0.825	P = 0.364

4.4.6. Section Summary

The results from this section answer research question 3, 'Can demographic, lifestyle, health and disabilities factors be identified as risk factors for injuries, accidents and falls of adults with learning disabilities?'

Epilepsy was identified as an independently predictive risk factor for incident injury, and autism was found to be a protective factor. Epilepsy was also found to be an

independently predictive factor for incident fall injury (epilepsy-related falls included). Urinary incontinence was found to be independently predictive of incident fall injury (epilepsy-related falls excluded), and repeated falls (three or more, with or without injury). Down syndrome was found to be a protective factor for both incident fall injury (epilepsy-related falls excluded), and repeated falls. The carer's views that the person they support is clumsy/accident-prone *and* that they were more likely to become injured at a particular time of year (Winter) were both associated with incident fall injury (epilepsy-related falls included), fall injury (epilepsy-related falls excluded), and repeated falls. Poor balance/coordination was also found to be associated with repeated falls. The only factor found to be associated with accidents other than falls was carers' views that most accidents are not preventable. These results are summarised in *table 4.33.*

Table 4.33. Summary of Independently Related Factors with Incident Injury/Falls

Time of measurement	**Incident injury**	**Fall injury (including epilepsy)**	**Fall injury (excluding epilepsy)**	**Repeated falls**	**Accident injury**
T1	Epilepsy	Epilepsy	No Down syndrome	No Down syndrome	-
T1	No autism		Urinary incontinence	Urinary incontinence	
T2		Clumsiness	Clumsiness	Clumsiness	Carer views on accidents
T2		Season	Season	Season	
T2				Poor balance	

4.5. Factors Perceived by Adults with Learning Disabilities and Their Carers as Contributing to Injuries, Falls and Other Accidents

4.5.1. Hazards Identified by Adults with Learning Disabilities and Their Carers

Twenty-three (20.4%) of the 113 adults with learning disabilities who experienced at least one injury that required medical or nursing attention/treatment in the 12-month period, and their carers, could not identify any hazards or factors that they felt had contributed to their injury incident/s. Of the remaining 90 (79.6%) adults with learning disabilities who could, 118 hazards were identified (*table 4.34*). Environmental factors (indoors and outdoors) followed by physical health factors were mentioned most often, accounting for 42 (35.6%) and 25 (21.2%) respectively of all 118 hazards mentioned/identified.

Table 4.34. Factors Contributory to Incident Injury Identified by the Adults with Learning Disabilities and Their Carers

	Number of times mentioned
Physical Health:	**25**
Epilepsy	8
Feeling dizzy	4
Poor mobility or balance	4
Previous fractures	3
Fainting	2
Arthritis	2
Osteoporosis	1
Suspected stroke	1
Environment (indoors):	**21**
Walking into furniture	7
Jamming digit in door/cupboard/drawer	3
Tripped over object	3
Falling off bed/seat/toilet from sitting position	3
Falling off bed from lying position	2
Slipping in bath	1
Wet floor/spillage	1
Loose toilet seat	1
Environment (outdoors):	**21**

Stairs/steps	8
Pavement kerb	5
Getting out/off of stationary vehicle	4
Moving car (road traffic accident)	3
Uneven road surface e.g. gravel	1
Self-harm	**15**
Self-injurious behaviour	12
Suicide attempt	3
Risk of burns or scalds	**9**
Electrical iron	4
Saucepan	2
Kettle	2
Shower	1
Food and Drink/Consumption	**6**
Alcohol consumption	4
Food poisoning	1
Choking	1
Misuse of aids or adaptations	**5**
Wheelchair brakes not on	2
Not securely strapped in wheelchair	2
Improper use of hoist	1
Harm	**4**
Another person (including attacks)	4
Other	**12**
Wandering unsupervised	3
Contact sport	2
Person was distracted	1
Hit by a falling object	1
Walking barefoot	1
Overstretching/straining part of body	1
Insect bite	1
Broken glass	1
Medication error	1

4.5.2. Carers' Views on Injuries, Falls and Other Accidents

How strongly the 446 carers agreed/disagreed with each statement (questionnaire items) on injuries, accidents and falls in relation to people with learning disabilities in general are presented in *table 4.35*. The results show that carer's tend to agree that people with learning disabilities are more prone to falling and having accidents, but also that most accidents are preventable.

Table 4.35. Carers' Views on Injuries, Accidents and Falls in Relation to People with Learning Disabilities

Statement	**Strongly Agree**	**Agree**	**Don't Know**	**Disagree**	**Strongly Disagree**
People with learning disabilities are more prone to falling than other people.	21 (4.7%)	185 (41.5%)	74 (16.6%)	155 (34.8%)	11 (2.5%)
People with learning disabilities are more likely to have accidents & become injured than other people.	22 (4.9%)	212 (47.5%)	64 (14.3%)	141 (31.6%)	7 (1.6%)
Most accidents are preventable.	36 (8.1%)	254 (57.0%)	89 (20.0%)	64 (14.3%)	3 (0.7%)

4.5.3. Section Summary

The results in this section consider the views of the adults with learning disabilities and their carers, addressing research question 5, 'What factors are perceived by adults with learning disabilities and their carers as contributing to injuries, accidents and falls of adults with learning disabilities?' Environmental and physical health factors were most commonly mentioned as being contributory, and thus are highlighted.

4.6. Aids and Adaptations, Risk Assessments, and Incident Reporting

4.6.1. Use of Aids and Adaptations

The adults with learning disabilities, and their carers where appropriate, were asked if they had any aids or adaptations in place at home to help prevent injuries. Their responses are reported in *table 4.36.* Special alarms were the most common type of aids or adaptations reported to be in place at home for 375 (73.4%) of all adults with learning disabilities, due to the high number of household smoke/fire alarms in situ.

Table 4.36. Aids and Adaptations in Place at Home to Prevent Injury (3 pages)

Aid or Adaptation	Proportion of Adults with Learning Disabilities N = 511 (100%)*
Special alarm:	**375 (73.4%)**
Smoke/fire alarm	355 (69.5%)
Emergency alert cord/button	32 (6.3%)
Door alarm	24 (4.7%)
Carbon monoxide detector	9 (1.8%)
Epilepsy alarm	8 (1.6%)
Did not specify	3 (0.6%)
Heat sensor alarm	2 (0.4%)
Vibrating Fire alert pillow	2 (0.4%)
Movement sensor alarm	2 (0.4%)
Portable intercom/monitor	1 (0.2%)
Pressure mat alarm	1 (0.2%)
Special bathroom aid:	**200 (39.1%)**
Hand/grab rails	79 (15.4%)
Temperature controlled water	67 (13.1%)
Bath/shower seat	60 (11.7%)
Walk in/wet floor shower	49 (9.6%)
Special bath	11 (2.2%)
Tracking system for hoist	11 (2.2%)
Bath thermometer	4 (0.8%)
Raised toilet seat	4 (0.8%)

Bath step	4 (0.8%)
Changing mat/station	3 (0.6%)
Bath chair lift	1 (0.2%)
Back rest on bath	1 (0.2%)
Special flooring:	**110 (21.5%)**
Non-slip floor surface	47 (9.2%)
Hard surface e.g. wooden	39 (7.6%)
Non-slip mats	22 (4.3%)
Special carpeting	5 (1.0%)
Cushioned flooring	1 (0.2%)
Did not specify	1 (0.2%)
Outdoor/garden equipment:	**74 (14.5%)**
Ramp	40 (7.8%)
Hand/grab rails	37 (7.2%)
Levelled path	2 (0.4%)
Secure gate	2 (0.4%)
Security lighting	1 (0.2%)
Special lifting aid:	**46 (9.0%)**
Hoist	38 (7.4%)
Stair lift	5 (1.0%)
Transfer slide	1 (0.2%)
Standing aid	1 (0.2%)
Did not specify	1 (0.2%)
Special bedroom aid:	**45 (8.8%)**
Bed sides	21 (4.1%)
Special bed/mattress	16 (3.1%)
Tracking system for hoist	11 (2.2%)
Commode	6 (1.2%)
Special lighting e.g. touch lamp	2 (0.4%)
Hand/grab rails	1 (0.2%)
Did not specify	1 (0.2%)
Special kitchen aid:	**22 (4.3%)**
Locked kitchen door	5 (1.0%)
Non-slip place mat	4 (0.8%)
Kitchen cupboard safety locks	2 (0.4%)

Plate guard	2 (0.4%)
Cooker guard	2 (0.4%)
Safety gate at kitchen door entrance	2 (0.4%)
Special cutlery	2 (0.4%)
Wheelchair level work top	1 (0.2%)
Locked drawer for knives	1 (0.2%)
Kettle holder	1 (0.2%)
Protective electrical iron cover	1 (0.2%)
Perching stool	1 (0.2%)
Did not specify	1 (0.2%)
Special body protective wear:	**6 (1.2%)**
Leg callipers	2 (0.4%)
Knee pads (for crawling)	2 (0.4%)
Epilepsy helmet	1 (0.2%)
Hip protectors	1 (0.2%)
Special protective gloves	1 (0.2%)
Other aids and adaptations:	**5 (1.0%)**
Fire guard	1 (0.2%)
Mobile ramp	1 (0.2%)
Special chair in living room	1 (0.2%)
Special lighting indoors	1 (0.2%)
Bed in living room	1 (0.2%)

*Figures do not add up to 100% because some adults reported having more than one aid or adaptation.

4.6.2. Risk Assessments

Two hundred and twenty eight paid carers (e.g. support workers or nursing/residential care staff) participated in these interviews and answered questions about individual (or individualised) risk assessments. One hundred and seventy-four (76.3%) of paid carers or their staff team had conducted individual risk assessments for the person they support at anytime, 43 (18.9%) had not, and a further 11 (4.8%) did not know.

Of the 174 paid carers who said individual risk assessment/s had been carried out for the person they care for/support, 135 (77.6%) said the risk assessment/s had been reviewed or

updated in the previous 12 months, 35 (40.1%) said the risk assessment/s had not been reviewed or updated in the previous 12 months, and 4 (2.3%) said they did not know.

Thus, 135 (60.1%) of all 228 paid carers reported risk assessments which had been carried out for individuals *and* reviewed or updated in the previous 12 months.

4.6.2.1. Specific Types of Risk Assessments

The 174 paid carers who said individual risk assessment/s had been carried out for the person they care for/support, were asked to list the specific areas of risk assessed. Their responses are presented in *table 4.37*. The most commonly conducted individual risk assessments were for personal hygiene/bathroom safety, household/kitchen safety, road crossing safety, and use of public transport. Only 16 (9.2%) individuals with learning disabilities had a risk assessment completed for their risk of falling.

Table 4.37. Specific Types of Individual Risk Assessments Completed by 174 (76.3%) of Paid Carers (2 pages)

	Paid Carers N = 174 (100%)*
Personal:	
Personal hygiene/bathroom safety	61 (35.1%)
Talking/answering door to strangers	3 (1.7%)
Budgeting skills	2 (1.1%)
Ability to use a telephone in an emergency	2 (1.1%)
Eating and drinking	7 (4.0%)
Use and maintenance of special bed	1 (0.6%)
Finger/toenail hygiene and care	1 (0.6%)
Use of a sensory room	1 (0.6%)
Household:	
Kitchen safety	39 (22.4%)
Use of electrical equipment (e.g. iron or kettle)	28 (16.1%)
Risk of scalding	7 (4.0%)
Bedroom safety	6 (3.4%)
Use/non-use of knives	2 (1.1%)
Risk of walking into furniture	2 (1.1%)
Environmental (outdoors):	

Road crossing safety	33 (18.9%)
Sports activities (e.g. swimming or horse riding)	16 (7.0%)
Holiday safety	13 (7.5%)
Use of escalators	1 (0.6%)
Transport:	
Use of public transport	20 (11.5%)
Travel as a car passenger	12 (6.9%)
Mobility:	
Risk of falling	16 (9.2%)
Use of stairs/steps	8 (4.6%)
Mobility	6 (3.4%)
Risk of wandering	5 (2.9%)
Wheelchair use and maintenance	4 (1.8%)
Support/care level needs:	
Support/care level needs	13 (7.5%)
General risk assessment	11 (6.3%)
Individual moving and handling	8 (4.6%)
Being out and about unsupported	5 (2.9%)
Physical health:	
Epilepsy	9 (5.2%)
Smoking	7 (3.1%)
Visual impairment	2 (1.1%)
Medication refusal	2 (1.1%)
Self-medication	2 (1.1%)
Prevention of pressure sores	1 (0.6%)
Incontinence management	1 (0.6%)
Harm or self-harm:	
Risk of drinking household cleaning products	1 (0.6%)
Living with someone who has problem behaviours	1 (0.6%)
Person's own problem behaviours	1 (0.6%)
Problem drinking (alcohol)	1 (0.6%)
Mental health:	
Person's mental health needs	1 (0.6%)
Phobia management (person's fear of dogs)	1 (0.6%)

*Percentages do not add up to 100% because paid carers listed all risk assessments conducted for the person they care for/support (more than one).

4.6.2.2. Paid Carer Training on Risk Assessments

Of the 228 paid carers, 142 (57.9%) had received training on risk assessments, 86 (37.7%) had not, and 10 (4.4%) did not know if they had received training.

Of the 142 (57.9%) who had received training: 101 (44.3%) had received specific training on risk assessments within the organisation they worked for; 22 (9.7%) had received training on risk assessments as part of other training (e.g. induction) within the organisation they worked for; and 7 (3.0%) had received training on risk assessments as part of their higher national certificate (HNC) or Scottish vocational qualification (SVQ) in social care or their degree course in social work.

4.6.2.3. Recording and Reporting Incidents

Paid carers were asked about any formal procedures that were in place at the supported living or nursing/residential care home they worked in for recording and reporting incidents: 47 (20.6%) paid carers stated that incidents were being recorded correctly both in-house/on-site (e.g. in individuals with learning disabilities' daily logs/diaries and/or a staff communication book) and at organisational level (incident form sent to head office) (*table 4.38*).

Table 4.38. Paid Carers Responses on How Incidents are Recorded in Their Place of Work

	Paid Carers N = 228 (100%)
In-house/on site only	23 (10.1%)
At organisational level only	152 (66.7%)
In-house/on-site and at organisational level	47 (20.6%)
Paid carer said there was no recording procedure in place	1 (0.4%)
Paid carer was not familiar with recording procedure	5 (2.2%)

Paid carers' responses on who is notified once an incident has occurred are presented in *table 4.39* (for personnel within their organisation) and *table 4.40* (for persons out with their organisation): 149 (65.4%) paid carers were only aware of incident-reporting

procedure as far as to their line manager within their organisation; and only 30 (13.2%) paid carers mentioned at least one other person out with their organisation who is notified.

Table 4.39. Paid Carers Responses on who is Notified Within Their Organisation Once an Incident Has Occurred

	Paid Carers N = 228 (100%)
Line manager	149 (65.4%)
Line manager and head office	61 (26.8%)
Line manager and Health and Safety Department	13 (5.7%)
Paid carer stated there was no notification procedure in place	1 (0.4%)
Paid carer was not familiar with who is notified	4 (1.8%)

Table 4.40. Paid Carers Responses on who is Notified Out With Their Organisation Once an Incident Has Occurred

	Paid Carers N = 228 (100%)*
No one out with their organisation was mentioned	198 (86.8%)
Person with learning disabilities' relative	19 (8.3%)
Person with learning disabilities' general practitioner (GP)	7 (3.1%)
Person with learning disabilities' care manager	3 (1.3%)
Person with learning disabilities' social worker	1 (0.4%)
Housing Association (if modifications required)	1 (0.4%)
Care Commission	1 (0.4%)

*Two paid carers gave more than one answer

4.6.3. Section Summary

The results in this section consider the measures that are put in place to assist adults with learning disabilities to live safely in their own homes and community environments, and demonstrate the extent to which they are or are not being utilised. These results are directed towards answering research question 6, 'To what extent are aids and adaptations, risk assessments, and incident reporting utilised?' They show the widespread use of aids and adaptations (which the former section demonstrated can actually contribute to injury in some cases), and risk assessments, but also highlight few risk assessments for falls, and

some differences in reporting procedures. They will be considered in more detail alongside the rest of this research project's results in the next 'Discussion' chapter.

4.7. Carers Injuries

4.7.1. Paid and Unpaid Carers Characteristics

Four hundred and forty-six carers supported the adults with learning disabilities they care/for support during their research interviews: 14 carers were present at more than one interview (460 (90%) of the adults with learning disabilities were supported). The characteristics of these carers are presented in *table 4.41* by carer type: paid carer e.g. support worker; or unpaid carer e.g. parent. There were highly significant age and gender differences between paid and unpaid carers, as unpaid carers were typically older parents, particularly mothers. Carers overall were significantly more likely to be female: 346 (77.6%) of all carers were female ($P < 0.001$).

Table 4.41. Carers Characteristics by Carer Type

	Paid carers N = 228	**Unpaid carers N = 218**	**χ^2/t-test**	**Significance**
Age in years:				
Mean	41	60	-17.982	$P < 0.001$
(Range, SD)	(21 – 68, 10.8)	(30 – 91, 12.2)		
Gender:				
Male	69	31	16.490	$P < 0.001$
Female	159	187		

Carers also provided information on their own experiences of any injuries from falls or other causes that required medical or nursing attention/treatment in the 12-month period.

4.7.1.1. Paid and Unpaid Carers Incidence of Injuries

Forty-four (9.8%) of the 446 carers experienced at least one injury that required medical or nursing attention/treatment in the 12-month period; 20 out of 228 (8.8%) paid carers, and 24 out of 218 (11.0%) unpaid carers. The difference in incident injury between the paid and unpaid carers was not significant ($P = 0.407$).

4.7.1.2. Paid and Unpaid Carers Types of Injury

Fisher's Exact Tests were used in the following analysis on paid/unpaid carers types (and causes) of injury instead of Chi-square statistics, due to the small size in cells.

The types of injury experienced at least once in the 12-month period by the paid and unpaid carers are reported in *table 4.42*: the unpaid carers were significantly more likely to experience broken bones. Straining/twisting a part of the body and bruising/pinching a part of the body were the most commonly reported types of injury for carers overall; 14 (3.1%) and 12 (2.7%) out of 446 carers respectively.

Table 4.42. Types of Injury Experienced by Paid and Unpaid Carers

SHS 2003 Categories	Paid Carers 228 (100%)	Unpaid Carers 218 (100%)	Significance
Broken bones	1 (0.4%)	7 (3.2%)	P = 0.036
Dislocated joints	0 (0%)	3 (1.4%)	P = 0.116
Losing consciousness	1 (0.4%)	0 (0%)	P = 1.000
Straining/twisting part of body	9 (3.9%)	5 (2.3%)	P = 0.317
Cutting/grazing part of body	4 (1.8%)	1 (0.5%)	P = 0.373
Bruising/pinching part of body	5 (2.2%)	7 (3.2%)	P = 0.568
Object stuck part of body	1 (0.4%)	0 (0%)	P = 1.000
Burning or scalding	0 (0%)	0 (0%)	---
Poisoning	0 (0%)	0 (0%)	---
Internal injury	0 (0%)	0 (0%)	---
Animal/insect bite or sting	0 (0%)	0 (0%)	---
Swelling or tenderness	3 (1.3%)	1 (0.5%)	P = 0.626
Other	0 (0%)	0 (0%)	---

4.7.1.3. Paid and Unpaid Carers Causes of Injury

The causes of injury experienced at least once in the 12-month period by the paid and unpaid carers are reported in *table 4.43*: the unpaid carers were significantly more likely to have experienced falls, trips and slips; and significantly less likely to have experienced a sports or recreational accident was of borderline significance. Falls were the commonest cause of injury for all carers (24 out of 446 carers, 5.4%).

Table 4.43. Causes of Injury Experienced by Paid and Unpaid Carers

SHS 2003 Categories	Paid Carers 228 (100%)	Unpaid Carers 218 (100%)	Significance
Fall, trip, slip	7 (3.1%)	17 (7.8%)	P = 0.027
Hit by a falling object	1 (0.4%)	1 (0.5%)	P = 1.000
Road traffic accident	3 (1.3%)	2 (0.9%)	P = 1.000
Sports/recreational accident	5 (2.2%)	2 (0.9%)	P = 0.061
Use of tool/implement/equipment	0 (0%)	0 (0%)	---
Burn or scald	0 (0%)	0 (0%)	---
Animal/insect bite/sting	0 (0%)	0 (0%)	---
Another person (e.g. attacks)	3 (1.3%)	4 (1.8%)	P = 0.719
Lifting	2 (0.9%)	0 (0%)	P = 0.499
Other causes	*1 (0.4%)	0 (0%)	P = 0.489

*Play-fight with her partner

4.7.2. Carers Injuries Compared with Adults with Learning Disabilities Injuries

Fisher's Exact Tests were also used in this section, comparing the types and causes of injuries experienced by carers with the same for the adults with learning disabilities they care for/support, due to cell size figures being small.

4.7.2.1 Types of Injury Comparison

The types of injury experienced at least once in the 12-month period by 44 (9.9%) of the carers were compared with the types of injury experienced by the 105 (20.5%) adults with learning disabilities they support (self-injury excluded) are reported in *table 4.44*. The carers were significantly more likely to have experienced straining/twisting a part of the body (borderline significance), but the adults with learning disabilities were significantly more likely to have experienced losing consciousness (borderline significance), cuts/grazes (highly significant), bruising/pinching part of the body (borderline significant), burns/scalds (highly significant), and swelling/tenderness (highly significant).

Table 4.44. The Types of Injury Experienced by Carers and the Adults with Learning Disabilities They Support

SHS 2003 Categories	Adults with Learning Disabilities 511 (100%)	Carers 446 (100%)	Significance
Broken bones	16 (3.1%)	8 (1.8%)	P = 0.187
Dislocated joints	3 (0.6%)	3 (0.7%)	P = 1.000
Losing consciousness	7 (1.4%)	1 (0.2%)	P = 0.074
Straining/twisting part of body	7 (1.4%)	14 (3.1%)	P = 0.062
Cutting/grazing part of body	38 (7.4%)	5 (1.1%)	P < 0.001
Bruising/pinching part of body	26 (5.1%)	12 (2.7%)	P = 0.058
Object stuck part of body e.g. ear	1 (0.2%)	1 (0.2%)	P = 1.000
Burning or scalding	9 (1.8%)	0 (0%)	P = 0.004
Poisoning	4 (0.8%)	0 (0%)	P = 0.128
Internal injury	0 (0%)	0 (0%)	---
Animal/insect bite or sting	1 (0.2%)	0 (0%)	P = 1.000
Swelling or tenderness	19 (3.7%)	4 (0.9%)	P = 0.004
Other	**1 (0.2%)	0 (0%)	P = 1.000

*N/A = not applicable, **near drowning.

4.7.2.2. Causes of Injury Comparison

The causes of injury experienced at least once in the 12-month period by the carers compared with the adults with learning disabilities they support are presented in *table 4.45*. The adults with learning disabilities were significantly highly more likely than their carers to have experienced injury from falls, trips or slips (although falls/trips/slips were the commonest cause for carers too), burns or scalds, and other causes.

Table 4.45. The Causes of Injury Experienced by Carers and the Adults with Learning Disabilities They Support

SHS 2003 Categories	Adults with Learning Disabilities 511 (100%)	Carers 446 (100%)	Significance
Fall, trip, slip	62 (12.1%)	24 (5.4%)	P < 0.001
Hit by a falling object	1 (0.2%)	2 (0.4%)	P = 0.601
Road traffic accident	3 (0.6%)	5 (1.1%)	P = 0.484
Sports/recreational accident	7 (1.4%)	7 (1.6%)	P = 0.729
Use of tool/implement/equipment	0 (0%)	0 (0%)	---
Burn or scald	10 (2.0%)	0 (0%)	P = 0.002
Animal/insect bite/sting	1 (0.2%)	0 (0%)	P = 1.000
Another person (e.g. attacks)	5 (1.0%)	7 (1.6%)	P = 0.412
Lifting	0 (0%)	2 (0.4%)	P = 0.217
Other causes	18 (3.5%)	1 (0.2%)	P < 0.001

4.7.3. Carers Injuries Compared with Regional General Population Injuries

4.7.3.1. Incidence of Injury Compared with Regional General Population

For the 1, 225 adults aged 16 years and over in the SHS 2003 Greater Glasgow region sample, the incidence of injury was 12.2% (149 people). Hence we would have expected 54 out of our cohort of carers in the same geographical region to have had incident injury if they had experienced a similar rate of injury over a 12-month period. As the incidence of at least one injury for the cohort of carers was 9.8% (44 people), the standardised injury ratio is actually 0.81 (95% CI 0.77 – 0.85).

The types and causes of injury experienced by all adults aged 16 years and over in the SHS 2003 are included in the appendix (*appendix 10*).

4.7.3.1. Types of Injury Comparison

The types of injury experienced at least once in the 12-month period by carers were compared with the same for adults in the SHS 2003 Greater Glasgow sub-sample (*table 4.46*): the carers were significantly less likely to have experienced cuts/grazes, and swelling/tenderness in particular, and burns/scolds was of borderline significance.

Table 4.46. Types of Injury Experienced by the Carers of Adults with Learning Disabilities Compared with Adults in the SHS 2003 Sample

SHS 2003 Categories	**SHS 2003 Greater Glasgow Sub-Sample N = 1, 225 (100%)**	**Carers N = 446 (100%)**	**Significance**
Broken bones	27 (2.2%)	8 (1.8%)	P = 0.604
Dislocated joints	3 (0.2%)	3 (0.7%)	P = 0.196
Losing consciousness	11 (0.9%)	1 (0.2%)	P = 0.149
Straining/twisting part of body	50 (4.1%)	14 (3.1%)	P = 0.374
Cutting/grazing part of body	38 (3.1%)	5 (1.1%)	P = 0.024
Bruising/pinching part of body	47 (3.8%)	12 (2.7%)	P = 0.261
Object stuck part of body	6 (0.5%)	1 (0.2%)	P = 0.457
Burning or scalding	8 (0.7%)	0 (0%)	P = 0.087
Poisoning	4 (0.3%)	0 (0%)	P = 0.227
Internal injury	6 (0.5%)	0 (0%)	P = 0.139
Animal/insect bite or sting	1 (0.1%)	0 (0%)	P = 0.546
Swelling or tenderness	56 (4.6%)	4 (0.9%)	P < 0.001
Other	1 (0.1%)	0 (0%)	P = 0.546

4.7.3.2. Causes of Injury Comparison

The causes of injury experienced at least once in the 12-month period by the carers were compared with the same for the adults in the SHS 2003 Greater Glasgow sub-sample (*table 4.47*): the carers were significantly more likely to experience injury from another person (including attacks), and significantly less likely to experience injury as a result of using a tool, implement or equipment.

Table 4.47. Causes of Injury Experienced by the Carers of Adults with Learning Disabilities Compared with Adults in the SHS 2003 Sample

SHS 2003 Categories	SHS 2003 Greater Glasgow Sub-Sample N = 1, 225 (100%)	Carers N = 446 (100%)	Significance
Fall, trip, slip	69 (5.6%)	24 (5.4%)	P = 0.843
Hit by a falling object	8 (0.7%)	2 (0.4%)	P = 0.631
Road traffic accident	6 (0.5%)	5 (1.1%)	P =0.158
Sports/recreational accident	22 (1.7%)	7 (1.6%)	P = 0.754
Use of tool/implement/ equipment	11 (0.9%)	0 (0%)	P = 0.045
Burn or scald	7 (0.6%)	0 (0%)	P = 0.110
Animal/insect bite/sting	1 (0.1%)	0 (0%)	P = 0.546
Another person (e.g. attacks)	7 (0.6%)	7 (1.6%)	P = 0.048
Lifting	5 (0.4%)	2 (0.4%)	P = 0.910
Other causes	0 (0%)	1 (0.2%)	P = 0.267

4.7.4. Carers Total Number of Injuries

The total number of incidences of injury for the 44 carers was 49: 2 experienced an injury on two separate occasions; and 1 experienced an injury on three separate occasions. As all 44 carers only experienced one injury at any one time, the total number of carer injuries also equals 49.

4.7.5. Carers Environmental Factors/Context

4.7.5.1. Contributory Factors or Hazards Identified

The 44 carers who experienced at least one incidence of injury in the 12-month period were asked to identify any hazards or factors they felt had contributed to their incidence/s of injury: 10 (22.7%) could not identify any hazards or factors at all. The total number of 34 hazards/factors identified, by the remaining number of 34 carers are reported in *table 4.48.*

Table 4.48. Contributory Factors for Incidences of Injury Experienced by the Carers

Factor identified:	**Number of times mentioned**
Environmental (indoors):	11
Stairs/steps	*6*
Wet floor/spillage	*2*
Tripped over an object	*2*
Falling off seat/toilet/bed	*1*
Environmental (outdoors):	5
Moving car (road traffic accident)	*3*
Climbing over a fence	*1*
Getting out/off a stationary vehicle	*1*
Physical Health:	4
Feeling dizzy	*2*
Overstretching/straining a part of the body	*2*
Harm:	4
Another person (e.g. attacks)	*4*
Food/Drink Consumption:	2
Alcohol-related	*2*
Other:	8
Contact sport	*5*
Hit by a falling object	*2*
Broken glass	*1*
Total	**34**

4.7.5.2. Exposure to Harm

Seven (1.6%) carers experienced injury from another person that required medical or nursing attention/treatment in the 12-month period: 5 (1.1%) from a person with learning disabilities they care for/support; and 2 (0.4%) from another person in an alcohol-related incident in/outside a pub.

Of the five carers who experienced injury from a person with learning disabilities they care/for support, three were paid carers (e.g. support workers) and two were unpaid carers (e.g. parents). Fifty-seven (12.8%) of all carers were exposed to challenging behaviours of adults with learning disabilities they either support on a daily basis (41, 18.0%) or care for

at home (16, 7.3% of unpaid carers). Five (8.8%) out of 57 carers who were exposed to challenging behaviour therefore, were injured as a result.

4.7.5.3. Environmental Context

The majority of the total number of carers injury incidents (n = 49) occurred at their own home (23, 46.9%). This was followed by outdoors (20, 40.8%), and at work (at the home of the person with learning disabilities they care for/support as a support worker) (4, 8.2%), at hospital as an in-patient (1, 2.0%), and unspecified (1, 2.0%). The carers were also most likely to seek medical or nursing attention/treatment for their injury at their local hospital's Accident and Emergency department (25, 51.0%), followed by a doctor (GP) or nurse at their GP surgery (18, 36.7%), their GP who then sent them to hospital (2, 4.2%), a nurse on site (2, 4.1%), a family member with medical expertise (1, 2.0%), and a local pharmacist (1, 2.0%).

4.7.6. Section Summary

The results in this section report the incidence, types and causes of injury experienced by carers of adults with learning disabilities, comparing paid carers with unpaid carers. The results in this section answer research question 7, 'Are carers of adults with learning disabilities more prone to injuries, accidents and falls when compared with a) the adults with learning disabilities they support, and b) published general population data?'

Carers were less likely to have experiences an injury than both the adults with learning disabilities, and the general population. Although they spend a large part of the day in the same environment as the people with learning disabilities, they have different types and causes of injuries. Their type and causes of injuries also differ from the general population, with notably, attack from another person being more commonly experienced: 8.8% of the 57 carers who care for a person with problem behaviours were injured as a result.

Chapter Summary

This chapter reports the results from the analyses of the data collected. The seven research questions have been answered.

This chapter has reported the cohort characteristics and demonstrated that there is no difference between people who participated and those who did not. It described the high incidence of injuries experienced by adults with learning disabilities, and how these differ

in type and cause compared with the general population. Personal, lifestyle, health and disabilities factors that predict injuries have been identified, plus the views of carers on what might be contributory factors. The use of aids and adaptations, risk assessments and training in these has been described.

The results demonstrate that for a community-based cohort of adults with learning disabilities (n = 511) injuries are common, experienced by 22.1% in a 12-month period, and more than half of these injuries are caused by falls (54.9%). Falls with or without injury are a major concern for adults with learning disabilities, just as much as they are for older adults without learning disabilities in the general population. Falls incidence with or without injury was 40.1% for adults with learning disabilities, compared with 28% - 35% for older adults in the general population (World Health Organization, 2008a), but they have a different pattern of related factors. The standardised incidence ratio for adults with learning disabilities aged 18 to 64 years was 1.63 (95% CI 1.55 – 1.71). Adults with learning disabilities also experience a different pattern of types and causes of injury compared with the general population; experiencing cuts/grazes more commonly and internal injury and straining/twisting a part of the body less commonly; as well as fall injury and injuries for other causes not relevant for the general population more commonly, and injury from the use of a tool/implement/equipment less commonly.

This PhD research project has identified for the first time, risk factors for injuries, falls and other accidents in community-based adults with learning disabilities. The presence of epilepsy was found to be an independently predictive factor for incident injury and incident fall injury (including seizure-related falls), and autism was found to be an independently protective factor for incident injury. Urinary incontinence of any type was also found to be an independently predictive factor for incident fall injury (excluding seizure-related falls) and repeated falls (three or more falls) with or without injury, whilst Down syndrome was found to be an independently protective factor for both of these fall/s outcomes. Poor balance/coordination was also found to be associated with incident accidental injury (other than fall injury). These risk factors identified are specific to the population with learning disabilities, with the exception of urinary incontinence, which has also been identified as a risk factor for falls in older adults without learning disabilities in the general population. None of the other risk factors previously identified for older adults without learning disabilities in the general population which were tested were found to be predictive/protective factors for adults with learning disabilities as well, which suggests injuries and falls being a major concern for both groups/populations but for different

reasons. The carer's view that the person with learning disabilities they care for/support is clumsy/accident-prone *and* that they were more likely to fall at a particular time of year (mainly Winter) were both found to be associated with incident fall injury (including epilepsy-related), fall injury (excluding epilepsy-related), and repeated falls. The carer's view that most accidents are not preventable was also found to be associated with incident accidental injury (other than fall injury).

Finally, the results contained within this thesis demonstrate that carers of adults with learning disabilities are less likely to experience injury compared with the general population in the same geographical region: standardised incidence ratio was 0.81, 95% (CI 0.77 – 0.85), but they are more likely to experience injury from another person (including attacks), most often in their caring/support role.

The implications of these findings for future policy and practise, research and education will be discussed in the next chapter.

CHAPTER 5:
DISCUSSION

Overview

The aims of this PhD research project, which were set out in the Research Aims and Questions chapter of this thesis, were to:

1. Determine the incidence and types and causes of injuries experienced by a community-based cohort of adults with learning disabilities.
2. Compare these findings with the same for the general population in the same geographical region.
3. Identify risk factors for injuries, accidents and falls.

A further aim was to:

4. Determine whether carers of adults with learning disabilities are more prone to injuries when compared with i) the adults with learning disabilities they support, and ii) the general population in the same geographical region.

These research aims were focused on establishing steps one and two of the four-key steps public health approach towards injury prevention (Mercy et al., 1993), which was set out in the Introduction chapter of this thesis. These first two steps are necessary, in order to be able to design, pilot-test, and evaluate interventions for injury prevention in the future (step three of four), and implement the most promising interventions on a broader scale (step four of four). This or a similar approach to falls and fall injuries in older adults in the general population is well-documented in the literature, whereby falls and fall injuries have been established as a major concern in older adults in the general population, and risk factors have been identified, informing interventions.

The results of this PhD research project will be discussed in this chapter in relation to the existing literature, in terms of what they do (or still do not) add to our understanding of the phenomena of injuries, falls and other accidents in adults with learning disabilities. The methodology and methods employed for this research project will also be discussed, both in terms of their strengths and limitations, as well as the implications of the findings from this research project for future work/research.

This discussion starts by largely discussing the answers to the research questions in the order they were presented.

5.1. The Incidence of Injuries, Falls and Other Accidents Experienced by Adults with Learning Disabilities

5.1.1. Cohort

One of the main aims of this research was to determine, for the first time, the incidence of non-fatal injuries, falls and other accidents experienced by a population and community-based cohort of adults with mild to profound learning disabilities over a 12-month period. There was a good response to participation in the study (63.9%). Additionally, there were no significant differences in gender, level of learning disabilities, accommodation type/living arrangement, and age between those adults with learning disabilities who did take part in this research project, and those who did not. This suggests that participants were representative of the wider population with learning disabilities. The ratio of males to females who did participate was as expected (53.4% to 46.6% respectively), given that there are more males than females with learning disabilities (NHS Scotland, 2005).

In terms of population size, Glasgow is the largest city in Scotland and the fourth largest city in the United Kingdom. It is estimated that one million of Scotland's five million population reside in the Greater Glasgow area, which encompasses the countryside around Glasgow and East Dunbartonshire, as well as the 570,000 in the city itself (General Register Office, 2008). The population of adults with learning disabilities (aged 16 years and over) residing in Greater Glasgow was previously ascertained through a detailed process to be 3.33 per 1, 000 general population (Cooper et al., 2007); which is in keeping with other large-scale population ascertainment (Farmer et al., 1993; McGrother et al., 2001; Van Schrojenstein Lantman De-Valk et al., 2006), and GP learning disabilities registers now maintained as part of the GP Quality and Outcome Framework.

5.1.1.1. Uptake

To the best of the author's knowledge, this is the first research project to investigate non-fatal injuries, falls and other accidents in a cohort of adults with learning disabilities that has not been restricted to nursing home residents (Lohiya et al., 1999; Hsieh et al., 2001; Chiba et al., 2009); users of a particular service or services (residential or vocational) (Grant et al., 2001; Donald Beasley Institute, 2002); or persons with profound learning disabilities (Hale et al., 2007). The first population and community-based study of injuries experienced by children and young adults with learning disabilities (aged 5 – 29 years), reported response rates of 80.0% (465 out of 579) for their longitudinal cohort six years later at follow up (T2), and 71.9% (110 out of 153) for their supplementary sample who

were recruited at T2 only (Sherrard et al., 2001a). The response rate for adults with learning disabilities in this PhD research project, regarding a two-year follow up period, is less than this at 63.9%. This is not surprising, given that most children live with their family, whereas most adults do not.

5.1.1.2. Exclusions

Ninety-nine (11.0%) of the T1 (baseline) cohort of adults with learning disabilities were excluded from this research project, due to serious illness/death to themselves or a close family member. Of these, 34 (3.8%) had died at some time prior to their two-year follow up. A meaningful mortality rate could not be calculated from this figure (percentage) because of the sample size which had not been recruited to address this question on death. It is not known how many of these deaths, if any, were due to injury. Previous research investigating fatal injuries of adults with learning disabilities has been restricted to secondary analyses of state/national data bases (Dupont et al., 1987; Strauss et al., 1998; Durvasula et al., 2002), or users of a specific service (Community Services Commission, 2001); with the exception of the Sherrard et al. (2001a) study on children and young adults with learning disabilities. An investigation of fatal injuries of adults with learning disabilities was beyond the scope of this PhD research project, but further study in this area would be worthwhile, to determine the extent of the seriousness of injury in this population.

A further 47 (5.2%) of the T1 cohort were unable to take part in this research project with their carers even if they wanted to, because they did not have decision-making capacity to consent, and they did not have a contactable nearest relative or welfare guardian to give their written consent by proxy, as required by the Adults with Incapacity (Scotland) Act. In fact, only two people had welfare guardians. The Adults with Incapacity (Scotland) 2000 Act (Scottish Parliament, 2000) was legislated to safeguard the welfare and finances of people who lack capacity, and it clearly sets out the importance of the welfare guardian's power of attorney role, encompassing all aspects of their lives (and not just their participation in research), but appears to have had little impact. There were no significant differences in levels of learning disabilities between those who did and did not participate, although the lack of welfare guardians for these adults with learning disabilities could potentially have impacted on the representativeness of these results (with fewer adults with severe or profound learning disabilities being included), as well as uptake.

5.1.2. Injury, Falls and Other Accidents Data Collected

This PhD research project collected self-reported data (and/or proxy data) on the number, types and causes of non-fatal injuries, falls and other accidents experienced by adults with learning disabilities over the previous 12 months. The questionnaire which was developed and used for data collection was designed to collect data on the types and causes of injuries and falls likely to be experienced by adults with learning disabilities, which would be comparable with published general population data for the same. Limitations of the data collection tool are discussed further in section 5.10.

5.1.2.1. Injury and Falls Definitions Used

Data was collected on injuries that required medical or nursing attention or treatment in the 12-month period. This definition was comparable with the published general population data (Scottish Executive, 2005), which was also self-reported and collected for a 12-month period. The adults with learning disabilities and their carers who took part in this research project only reported physical injuries, all of which were recognisable as physical injuries using the ICD-10 (World Health Organization, 2007) chapters XIX (for types of injury) and XX (for causes of injury) as a guide. No psychological injuries (e.g. post traumatic stress, which are included elsewhere in the ICD-10) were reported by the adults with learning disabilities and their carers (or for the general population in the SHS 2003 either). This is in keeping with other studies. It is not known whether this was due to the participants having not experienced any psychological injuries, having not recognised psychological injury as such nor felt it relevant; or the research instrument/procedure not being able to collect this type of data because there was not enough emphasis on the consequences of their injury incidents (participants were only asked about immediate attention/treatment), and/or the 12-month period was not long enough for consequences of injury that may occur over time to develop.

For all injuries reported, data was also collected on antecedents (hazards identified) and immediate consequences (treatment/attention), as well as estimated frequencies of falls and accidents (other than falls) that did not necessarily result in injury. This additional descriptive data is useful for making sense of injuries and falls/accidents which can different meanings for different groups (from social and health care professionals, to researchers, to research participants) (Gillespie et al., 2009; Zecevic et al., 2006).

At the time of conducting the data collection phase of the research for this PhD project, which commenced in 2004, a current definition of a fall was ‘an event that results in a

person coming to rest inadvertently on the ground or other level, other than as a consequence of sustaining a violent blow, loss of consciousness, sudden onset of paralysis as in a stroke or epileptic seizure' (O'Neill et al., 1996). As stated in the Methods chapter of this thesis however, it was not suitable to use this definition in its entirety with people with learning disabilities who are known to experience a much higher prevalence of epilepsy when compared with the general population (Lhatoo et al., 2001), and the second part '…other than as a consequence of sustaining a violent blow, loss of consciousness, sudden onset of paralysis as in a stroke or epileptic seizure' was removed. More recently, the Prevention of Falls Network Europe (ProFANE) has reached a consensus and adopted a broader and simpler definition of a fall, which is 'an unexpected event in which the participants come to rest on the ground, floor, or lower level' (Lamb et al., 2005). The amended fall definition which was used in this PhD research project is more in keeping with the definition that is currently recommended; this demonstrates the usability of the current definition, as intended, to include falls from all causes (Lord et al., 2007), and for it to be used with groups/populations other than older adults. Lamb et al. (2005) also recommended that, in terms of a working definition, researchers should consider a lay perspective when asking participants about falls. In this PhD research project, participants were only asked whether or not they had 'fallen' in the previous 12 months, and if yes, whether or not they had become injured as the result of a 'fall'. The use of a lay perspective is particularly pertinent when conducting research which is reliant on recall with adults with learning disabilities, who can experience problems with communication and understanding, and their carers.

5.1.3. Incidence of Intentional and Unintentional Injuries

The incidence of at least one intentional/unintentional injury that required medical or nursing attention or treatment in the 12-month period is 22.1% (113 people) for the whole sample (n = 511) when self-injury is included, and 20.5% (105 people) when self-injury is excluded. Self-injury is more common in adults with learning disabilities. This percentage (number) is double the 11% (30 out of 268 people) reported by Hsieh et al. (2001) for adults with learning disabilities (aged 30 years and over) living in nursing homes who experienced at least one injury that required medical treatment living in a 12-month period. It was anticipated that injury incidence would be higher for the adults with learning disabilities in this PhD research project, due to the protected living environment for the adults with learning disabilities in that study. 53.6% (75 out of 140) of the total number of injury incidents reported by the adults with learning disabilities in this PhD research project occurred at home.

The standardized incidence ration reported in this PhD research project illustrates the higher rate of injuries experienced by adults with learning disabilities, and different patterns of health of adults with learning disabilities compared with the general population, which has implications. Incident injury due to falls was 12.1% (62 people), falls excluding epilepsy-related falls was 10.4% (53 people), due to accidents (other than falls) was 8.4% (43 people), due to other people's problem behaviours (harm) was 1.0% (5 people), and due to self-injury was 2.3% (12 people). Fall injury was also reported to be the commonest cause of injury for adults with learning disabilities in nursing homes (Hsieh et al., 2001), even when epilepsy-related falls are excluded. Epilepsy is also more common in adults with learning disabilities. Lhatoo et al. (2001) reported that people with learning disabilities are about fifty times more likely to have epilepsy than people without learning disabilities in the general population. More than one-third of the 32.4% (162 people) adults with learning disabilities in this cohort who have epilepsy experienced at least one epilepsy-related fall in the 12-month period.

The incidence of at least one self-injury that required medical or nursing attention or treatment in the 12-month period increases from 1.6% (8 people) to 2.3% (12 people) if attempted suicide is included. Self-injury (including suicide attempts) was excluded from subsequent analyses because, as will be demonstrated in the sections to follow, self-injuries (including suicide attempts) were relevant for adults with learning disabilities, but not reported by/for their carers or the general population in the SHS 2003 (Scottish Executive, 2005) for their own injuries. It is not known whether self-injury and suicide attempts, which can be sensitive topics, are more readily reported for adults with learning disabilities because in many instances for example, they are reported by their carers by proxy.

Incidence of at least one fall with or without injury in the 12-month period was 40.1% (205 people), and incident of at least one accident (other than a fall) was 11.5% (59 people). Women with learning disabilities were significantly more likely to experience at least one fall with or without injury than men with learning disabilities ($p = 0.014$). This data on non-injurious as well as injurious falls and other accidents has potential to increase our understanding of injuries, falls and other accidents in adults with learning disabilities, and allow earlier intervention to prevent injuries, falls and other accidents (Zecevic et al., 2006; Gillespie et al., 2009). Of the 40.1% (205 people), 22.5% (115 people) had fallen more than once, and 16.8% (86) are described in this PhD research project as experiencing repeated (or frequent) falls with or without injury (three or more falls). Falls clearly are a

significant problem in this population, and it is surprising how little previous research there has been on this topic.

Three other studies have investigated the incidence of falls with or without injury in adults with learning disabilities but their samples were restricted to adults with learning disabilities who use residential and vocational services (Donald Beasley Institute, 2002), live in residential campus-based care (Wagemans et al., 2006) and a nursing home (Chiba et al., 2009). The Donald Beasley Institute reported incidence of at least one fall over a 12-month period to be 14.3% (100 out of approximately 700 people), and Wagemans et al. (2006) reported incidence of at least one fall over a 33-month study period to be 61% (205 out of 338 people), of whom 29% (97 out of 338 people) had experienced repeated falls. Chiba et al. (2009) reported that 28.5% (41 out of 144 people) had experienced two or more falls over a three-month study period. The studies by the Donald Beasley Institute (2002) and Wagemans et al. (2006) however, were reliant on non-standardised data collection from care and support staff, thus there may be issues in reliability. Chiba's reported incidence of falls appears somewhat high for a 3-month study period (and it is not known what the incidence would have been if the adults with learning disabilities who were wheelchair users in the same nursing home had not been excluded), given that the literature on falls in older adults without learning disabilities demonstrates that approximately 30% to 50% of older adults living in long-term institutions fall each year (over a 12-month period), and 40% of them experience recurrent falls (World Health Organization, 2008a; 2008b). There is also some confusion between the fall definition they used in their study and their results. A fall was defined as 'an event that resulted in a person coming to rest inadvertently on the ground or other lower level not due to any intentional movement, a major intrinsic event, or an extrinsic force' (Chu et al., 2006), yet epilepsy (an intrinsic factor) was identified as one of their three independently associated risk factors for falls (paretic conditions and advancing age being the other two). The participants in the study conducted by Chiba et al. (2009) were restricted to a nursing home which provides care to adults with severe to profound learning disabilities in particular, and the level of learning disabilities distribution is skewed towards severe/profound (21, 14.6% had mild/moderate learning disabilities, and 123, 85.4% severe/profound). These authors did not find the person's level of learning disabilities to be an independently associated risk factor for falls, but it may be reasonable to suggest that all of the adults with learning disabilities included in their study had a high level of dependency/care needs to be resident in that particular care facility.

Considering the findings contained within this thesis within the context of the previous literature, shows that, on balance, the incidence of falls and fall-related injury reported in this thesis is contributing new knowledge, of clinical relevance, in view of the limitations of previous studies.

5.2. Types and Causes of Injuries Experienced by Adults with Learning Disabilities

5.2.1. Types of Injury

The types and causes of injury experienced at least once in the 12-month period, that required medical or nursing attention or treatment, are presented throughout this thesis using the SHS 2003 (Scottish Executive, 2005) categories for both, for consistency of reporting and discussing the results. Injury data collected on the adults with learning disabilities which did not correspond with any of the types and causes of injury categories relevant for the general population in the SHS 2003, were listed under the 'other' categories. The only other type of injury listed for the adults with learning disabilities was near drowning (0.2%, 1 person). The cause of this other type of injury identified will be discussed in the next section.

The five most commonly reported types of injury experienced at least once by the whole cohort (n = 511) in the 12-month period, that required medical or nursing attention or treatment, were cuts and grazes (7.4%, 38 people), bruising or pinching a part of the body (5.1%, 26 people), swelling or tenderness (3.7%, 19 people), broken bones (3.1%, 16 people), and burns or scalds (1.8%, 9 people).

5.2.1.1. Broken Bones (Fractures)

Previous research included in the Introduction chapter of this thesis has demonstrated that people with learning disabilities may be at increased risk of fractures due to a number of factors which affect bone density and osteoporosis e.g. anticonvulsant medications, limited mobility, Vitamin D deficiency (e.g. through time spent indoors) (Angelopoulou, 1999; Lohiya et al., 1999; Schrager et al., 2007). Fractures were the fourth most common type of injury identified for 3.1% (16) adults with learning disabilities in this PhD research project, but the incidence of fractures was not found to be significantly different for the adults with learning disabilities (aged 18 – 64 years) when compared with 2.0% (18) adults without learning disabilities (aged 18 – 64 years) in the same Greater Glasgow region ($p = 0.147$).

The results of this PhD research project do not contribute much to the literature on fracture risk in people with learning disabilities, as the percentage who had experienced at least one fracture in the 12-month period was felt to be too small to analyse further. Fracture risk in people with learning disabilities is of related interest to this PhD research project though, and previous research on this included in the Introduction is useful for highlighting for example, the problems associated with identifying fractures/injuries in people with learning disabilities who, due to the severity of their learning disabilities, cannot identify an injury or verbalise its effects (Lohiya et al., 1999). Injuries could have been under-reported in this PhD research project for this reason.

5.2.2. Causes of Injury

The six most commonly reported causes of injury experienced at least once by the whole cohort (n = 511) in the 12-month period were: falls, trips and slips (12.1%, 62 people); other causes (not reported for the general population) (3.5%, 18 people); burn or scald (2.0%, 10 people); sports or recreational accident (1.4%, 7 people); another person (e.g. attacks) (1.0%, 5 people); and road traffic accidents (0.6%, 3 people). Whilst some of these are low frequency e.g. road traffic accidents, they still carry important messages. All three of the adults reported that they were out and about in their local community on their own, unsupported at the time of the injury. Road crossing safety awareness might have prevented these injuries.

5.2.2.1. Falls, Trips and Slips

Falls, trips and slips were the commonest cause of injury. This is similar to the commonest cause of injury reported for community-based children (aged 5 – 14 years) and children/young adults (aged 15 – 29 years) in the Sherrard et al. (2001a) population-based study. Falls and fall injuries are a major concern in persons with learning disabilities. Whilst falls are recognised as an important problem for elderly people in the general population, this demographic is not the same for the learning disabilities population. For people with learning disabilities, falls have high incidence across all ages from childhood through adulthood, and into older age. This thesis did not find any higher rate for the older adults compared with the adults aged 18 - 64 years. This was not investigated further, although one might speculate that some of the factors that contribute to falls might be associated with a shorter life span (e.g. epilepsy and urinary incontinence). Additionally, the elderly group, whilst starting to acquire age related health needs are less likely to have longer standing disabilities (as people with the most severe disabilities have a shorter life

span) and may therefore paradoxically be healthier in some aspects of health which may impact on injury rate.

5.2.2.2. Other Causes (Not Relevant for the General Population)

Other causes (not reported for the general population) were the second most common cause of injury reported for 3.5% (18 people) of the whole cohort. These other causes were: walking/banging into furniture; unknown causes; carer's misuse of equipment (e.g. wheelchair or hoist); poisoning (drug administration error, and food poisoning); and choking.

The other causes of injury reported for the adults with learning disabilities but not the Scottish general population in the SHS 2003 (Scottish Executive, 2005) demonstrate the different pattern of injuries experienced by adults with learning disabilities, and the particular focus/attention required for investigating injuries in people with learning disabilities. The study of children/adults with learning disabilities by Sherrard et al. (2001a) highlighted poisoning, immersion (drowning), aspiration (choking), and self-injury (described earlier), as common causes of injury for persons with learning disabilities, so there does seem to be some similarities in these findings across childhood and into adulthood.

The other causes of injury reported for the adults with learning disabilities draw our attention to environmental considerations and the role of carers, in terms of adopting strategies/interventions to prevent injuries in the future. Some of these injuries were caused by the carer's misuse of equipment such as a hoist or wheelchair, for example, and the drug administration errors reported were also due to carer/pharmacist error. In a previous study of an estimated 700 adults with learning disabilities (aged 18 years and over) who used residential and vocational services in the same geographical region, the Donald Beasley Institute (2002) actually found being struck by/against an object (e.g. banging in to an object/furniture) to be the most commonly reported cause of injury, and falls the second most common (44%, 261 people and 31%, 184 people respectively). These authors collected data on both injuries that did require treatment/attention, and injuries that did not; and that is probably why being struck by/against and object was a more common cause than falls in this instance. Despite this, it does add further credence to the findings in this thesis.

The ‘other causes’ category of injury also draws our attention to the potential severity of injuries reported. For example, the one incidence of choking would have resulted in death if the person had not received immediate attention/assistance, and the one episode of near drowning, which occurred as a result of carer’s neglect/misuse of equipment (support worker’s failure to apply wheelchair brakes whilst stopping near a canal), would also have resulted in death if no action had been taken. Sherrard et al. (2001a) investigated non-fatal and fatal injuries in their study of children and young adults with learning disabilities, compared with the same for the general population, and calculated standardised injury mortality and morbidity ratios of 8 and 2 respectively for children/young adults with learning disabilities. Major contributors to this excess were falls, asphyxia, and drowning. Drowning was also highlighted in the Community Services Commission (2001) audit of deaths in Australia.

For some injuries that had been sustained, their cause could not be determined. This may also be due to persons with more severe/profound learning disabilities being unable to identify their injuries or communicate their effects (Lohiya et al., 1999); this again, is highlighted as a concern, and demonstrates the vulnerability of this group.

5.2.2.3. Burns or Scalds

Burns or scalds were also a common type and cause of injury reported for the adults with learning disabilities in this cohort. All of the burns/scalds reported were caused by either spilling a hot drink or use of kitchen equipment (an electric kettle or iron), with one exception. This would therefore appear to be an important issue to address in risk assessments. One of the adults with learning disabilities experienced severe burns/scalds as a result of hot shower water at home.

In Scotland, the Building (Scotland) Amendment Regulations Act (2007) has ensured that all new build and extensively refurbished domestic properties must have thermostatic mixing valves (TMVs) fitted, to regulate hot water temperature to a maximum of 48 degrees centigrade, thus preventing injury/death from hot water scalds/burns). Existing domestic properties (not due for refurbishment) however, are not covered by this Act, and are still reliant on the good practise of supported living service providers and housing associations, and informed parents/relatives.

5.2.3. Severity of Injuries

All of the injured participants in this PhD research project provided a description of each injury incident they experienced, and its severity. In some cases, injuries had been severe enough to require hospital admission (4.1%, 21 people). The adult with learning disabilities who experienced burns/scalds as a result of hot shower water for example, spent fourteen days in hospital for treatment as a result. The methods employed for data collection in this PhD research project however, did not set a criteria or standard for reporting injury severity. This type of information on injury severity would have been useful for determining the consequences, impact, and economic costs of injuries, and would usefully be studied in more detail in future research.

5.3. Incidence, Types and Causes of Injury Compared with the General Population

5.3.1. Incidence of Injury

The standardised incident injury ratio was 1.63 (95% CI 1.55 – 1.71); which means that the adults with learning disabilities were 1.63 times more likely to experience at least one injury in the 12-month period, compared with the adults without learning disabilities in the general population. This finding is very similar to that reported by Sherrard et al. (2001a), who found the injury morbidity ratio for children/young adults aged 5 – 29 years with learning disabilities to be 2. Children *and* adults with learning disabilities do experience a higher rate of injuries.

This is one of the most important findings in this thesis. To date, injuries have been overlooked in this population. Prevention strategies have been geared towards the needs of the general population, who are actually at lesser risk. Considerable investments have been made in Scotland to use multi-component interventions to address falls for the elderly via community teams. This thesis now highlights the needs of the learning disabilities population.

5.3.2. Types and Causes of Injury

The adults with learning disabilities (aged 18 – 64 years) in this PhD research project also experienced a different pattern of injuries, compared with the adults without learning disabilities (aged 18 – 64 years) in the SHS 2003 regional general population. In particular, falls, trips and slips were highly significantly more frequent in the learning disabilities population, and do require to become a focus of greater attention. ‘Other causes’ which are not relevant for the general population were, of course, all highly significantly more

common. Use of tools and equipment were less common. Falls/trips/slips and 'other' causes were the two most commonly reported causes of injury for the adults with learning disabilities, and their lack of injury from the use of a tool/implement/equipment is not surprising, and probably due to them being less likely to be in employment and using tools. This does highlight however, how reliance on strategy and policy developed for the majority on the population can have a negative impact on minority groups – through not addressing their needs and hence undermining the inequality gap.

5.4. Risk Factors for Injuries, Falls and Other Accidents

The table below is that previously presented in section 4.4.6 of the results, summarising the independently related factors to each of the five outcomes.

Table 4.33. Summary of Independently Related Factors with Incident Injury/Falls

Time of measurement	**Incident injury**	**Fall injury (including epilepsy)**	**Fall injury (excluding epilepsy)**	**Repeated falls**	**Accident injury**
T1	Epilepsy	Epilepsy	No Down syndrome	No Down syndrome	-
T1	No autism		Urinary incontinence	Urinary incontinence	
T2		Clumsiness	Clumsiness	Clumsiness	Carer views on accidents
T2		Season	Season	Season	
T2				Poor balance	

5.4.1. Predictive Risk Factors

Twenty two T1 (baseline) factors were investigated in this PhD research project to determine whether they could be identified as independently predictive risk factors for any of these five outcomes: incident injury; incident fall injury (including epilepsy-related); incident fall injury (excluding epilepsy-related); repeated falls (≥ 3 falls) with or without injury; and incident accident injury (other than fall injuries).

5.4.1.1. Predictive Factors for Incident Injury

Epilepsy was found to be a predictive factor for incident injury, and autism was found to be a protective factor. This compares with the previous work of Hsieh et al. (2001), who found epileptic seizures (occurring monthly or more frequently), destructive behaviour, and antipsychotic drugs to be independently predictive factors for incident injury in nursing home residents with learning disabilities. Sherrard et al. (2002) also found the presence of epilepsy to be an associated (rather than predictive) risk factor for injuries in children/young adults with learning disabilities, as well as psychopathology (emotional and behavioural problems), and an overly sociable temperament; and that being blind, deaf or immobile reduced risk. In this thesis, problem behaviour of any type was not found to predictive of incident injury, and nor was number of drugs, sensory impairments, or immobility, or mental ill-health. Hsieh et al. (2001) were the only authors identified from the literature who had also investigated predictive (and not associated) risk factors for injuries and falls in people with learning disabilities.

This is the first time autism has been investigated as a potential factor. Possible explanations are that adults with autism may be less inclined to interact with their environment, thus be less at risk of injury, or in some instances, a person with autism may be more precise and careful or repetitive and so well-rehearsed in their movements/mannerisms (Spiker et al., 1993). Alternatively, there could be some common underlying factor that both increases risk of autism and reduces it for injuries. These comments are, however, purely speculative, and the study results could even be spurious.

5.4.1.2. Predictive Factors for Incident Fall Injury (Including/Excluding Epilepsy-Related)

In this PhD research project epilepsy was the only predictor of incident fall injury, including epilepsy-related falls. This compares with Hsieh et al. (2001), who found older age (≥ 70 years), being ambulatory, and epileptic seizures (occurring less than once a month) to be predictive of incident fall injury, including epilepsy-related, in nursing home residents with learning disabilities; but not gender, level of learning disabilities, and poor physical health. Wagemans et al. (2006) also found epilepsy, anti-epileptic drugs, advancing age, and being ambulatory to be associated risk factors for fall injury in campus-based residents with learning disabilities, as well as fractures in the past, and visual impairment. These authors however, did not state the p-values for these associations, nor is it clear whether they used a numeric or categorical age variable. Hsieh et al. (2001) used a categorical age variable, whereas the author in this PhD research project used a numeric

age variable. Wagemans et al. (2006) stated that they had found no significant associations between hypertensive drugs, psycho-pharmaceutical drugs, Down syndrome, diplegia, gender, hypotonia, orthopaedic problems, and hearing impairment for incident fall injury in their study. Wagemans et al. (2006) did not consider or conduct further analyses to explain both epilepsy *and* epilepsy-related drugs being associated with fall injury in their study. In other words, they did not account for interactions. They also reported the same significantly associated factors and not associated factors for repeated falls, as they did for fall injury.

Grant et al. (2001) found co-morbid symptoms to be significantly associated with injurious falls in residents with learning disabilities, but not gender, level of learning disabilities, age, physical/sensory impairment, place of residence (group home or institution), and whether the person's freedom of movement was restricted by living in a locked ward. Only adults with learning disabilities who were ambulatory were included in their study.

As epilepsy was the only one of 22 factors investigated in this PhD research project which was identified as being predictive of fall injury, including epilepsy-related fall injuries, the next step in the regression analyses was to remove epilepsy-related fall injuries and re-investigate, given the burden of epilepsy on falls. This time, urinary incontinence (of any type) was identified as an independently predictive factor for fall injuries, excluding epilepsy-related fall injuries, and Down syndrome (OR 0.416) was found to be a protective factor. Mixed incontinence has been identified as a risk factor for falls in older adults without learning disabilities in the general population. Mixed incontinence is defined as a leakage associated with urgency and exertion, effort, sneezing or coughing (World Health Organization, 2008a). The identification of these predictive/protective factors demonstrate the importance of considering fall injury with and without epilepsy-related fall injury included separately in studies concerning people with learning disabilities, given the much higher prevalence of epilepsy in this group/population (Lhatoo et al., 2001). It is difficult to draw together the findings from this study with those of Hseih et al. (2001), Wagemans et al. (2006), and Grant et al. (2001), in view of the considerable methodological differences, and sampling.

5.4.1.3. Predictive Factors for Repeated Falls

Urinary incontinence (of any type) was also found to be an independently predictive risk factor for repeated falls (≥ 3 falls) with or without injury in this PhD research project, and Down syndrome was found to be independently protective. The reasons for this are not at

all clear for either of the factors identified, but they could be physiological. Adults with Down syndrome for example, are more likely to have short stature, and to be obese (Bell et al., 1999), hence have a different centre of gravity than those of normal weight. Adults with Down syndrome also have different walking patterns when compared with other people (slower walking with shorter, wider strides, spending more time in both stance and double support) (Smith et al., 2009), and characteristic foot shape (flat feet) and deformity (Concolino et al., 2006). Such considerations at this stage however, can only be viewed as speculative.

Chiba et al. (2009) found older age (50 years and over), epilepsy, and paretic conditions to be associated factors for two or more falls with or without injury in nursing home residents with learning disabilities. The associations in the study conducted by Chiba et al. (2009) were based on observations over a 3-month period only; and their finding that age 50 years and over are a risk factor for repeated falls is subject to interpretation, when compared with the findings by Hsieh et al. (2001) for incident fall injury. Hsieh et al. (2001) found age 70 years and over to be a predictive factor for fall injury in nursing home residents, thus they did not find age ranges 50 – 59 years or 60 – 69 years to be predictive of fall injury, or any of the age categories at all to be independently predictive of incident injury or accidental injury (other than fall injury). Evidence synthesis is hindered by differing methodologies and sampling.

5.4.1.4. Incident Accidental Injury (Other than Fall Injury)

None of the 22 T1 factors tested in this PhD research project were found to be predictive of accidental injury, for accidental injuries other than fall injuries. This differs from with Hsieh et al. (2001) who found adaptive behaviour, good physical health, and destructive behaviour to be predictive risk factors for accidental injuries (other than fall injuries) in nursing home residents with learning disabilities. Whether these differences are explained by the different study populations is unclear.

5.4.2 Associated Risk Factors

Of the twelve factors investigated for risk of injury, fall injury, and accidental injury (other than fall injury) by Hsieh et al. (2001) in their study of nursing home residents with learning disabilities, eleven were predictive (using data collected at T1, baseline) and one, which was residential status at the time of the study's follow-up, was associative. (The latter was not found in their study to be associated with any of the three outcomes). It is not good practise to include predictive and associative factors in the same multivariate

analyses, because ultimately, they are not investigating the same things; cross-sectional associated factors are not predictive, and including them can weaken the model.

In this PhD research project, an additional nine T2 factors were investigated separately for their possible associations with each of the five outcomes: incident injury; incident fall injury (including epilepsy-related); incident fall injury (excluding epilepsy-related); repeated falls (≥ 3 falls) with or without injury; and incident accidental injury (other than fall injuries). Separate multivariate regression analyses were conducted for this purpose.

5.4.2.1. Associated Factors for Falls and Fall Injuries

The carer's view that the person with learning disabilities they care for/support is clumsy/accident-prone *and* that they were more likely to become injured at a particular time of year (season, mainly Winter) were both found to be associated with three outcomes: incident fall injury (including epilepsy-related); fall injury (excluding epilepsy-related); and repeated falls (≥ 3 falls) with or without injury. Poor balance/coordination was also found to be associated with repeated falls (≥ 3 falls) with or without injury. Poor balance/coordination has previously been identified as a risk factor for falls in older adults without learning disabilities in the general population (World Health Organization, 2008a). There is also a suggestion in the literature on older adults without learning disabilities (Lord et al., 2007) that seasonal/weather factors may be associated with incidence of falls/fall injuries, although there is no conclusive evidence for this as yet. Intuitively, one might expect poor balance to contribute to falls, and this does point to possible actions that might be beneficial e.g. exercises or Vitamin D, to improve muscle strength, balance and co-ordination.

Interestingly, and out of keeping with the literature for the older general population, carer's views on whether the person they care for has a fear of falling was not found to be significantly associated with any of the five outcomes.

5.4.2.2. Associated Factor for Accidental Injury (Other than Fall Injuries)

The only one of the nine factors found to be significantly associated with incident accidental injury (other than fall injuries) was the carer's view that most accidents are *not* preventable ($p = 0.020$). It is not clear whether the carer's view that most accidents are *not* preventable - which does demonstrate a lay persons' different perspective of accidents from that of a public health view (Girasek, 1999) – reflects accurate observations or contributes to accidents through nihilism, and e.g. failure to complete risk assessments.

5.5. Factors Perceived by Adults with Learning Disabilities and Their Carers as Contributing to Injuries, Falls and Other Accidents

One hundred and eighteen hazards/factors were identified by the adults with learning disabilities and their carers, which they perceived had contributed to their injury incidents. Of these physical health factors, environmental factors (indoors), and environmental factors (outdoors) were the most commonly reported. Unsurprisingly, epilepsy was the most common physical health factor reported, followed by feeling dizzy and poor mobility/balance. Walking/banging into furniture was the most commonly reported indoor environmental hazard, and stairs/steps followed by pavement kerb were the most commonly reported outdoor environmental hazards.

These hazards or factors identified by the adults with learning disabilities and their carers add confirmation to the predictive/associated factors and causes of injury identified in the regressions earlier in the thesis; epilepsy and poor balance/coordination in particular, as well as the problem of walking/banging into furniture. These perceived contributory factors also indicate a need to pay more attention to physical health and environmental factors in future studies investigating injuries, falls and other accidents in people with learning disabilities. This particularly refers to designing studies which utilise suitable fall definition/s (which include falls as a result of physical health conditions/events), and the investigation of environmental factors as potential risk factors. A key reason for better understanding of environmental factors is that these are potentially modifiable.

5.6. Aids and Adaptations, Risk Assessments and Incident Reporting

Participants were asked about any aids and adaptations they had in situ at home to help prevent injuries, falls and other accidents. Paid carers (n = 228) were also asked about any risk assessments they and/or their staff team had carried out for the person they care for/support, as well as procedures that were in place at their work (the person with learning disabilities' home) for reporting and recording injury incidents. This was to consider the measures that are put in place to assist adults with learning disabilities to live safely in their own homes and community environments, and gauge the extent to which they are or are not being utilised.

5.6.1. Aids and Adaptations

The majority of adults with learning disabilities in the whole cohort had a special alarm in place at home to promote their safety, although most of these alarms were standard household smoke detector/fire alarms, and bearing in mind that many adults with learning disabilities have hearing impairment/s (27.4%), only 0.4% had a vibrating smoke/fire alert pillow. Only 1.6% had an epilepsy alarm, despite 32.4% having epilepsy. This suggests such devises might be being under-utilised.

The next most commonly reported type of aids and adaptations was special bathroom aids, of which hand/grab rails were the most common. Only 13.1% reported having temperature controlled hot water, with a further 0.8% having a bath thermometer in situ to be able to check the temperature before bathing. This is despite shower/bath water scalding being highlighted in this PhD research project as a cause of serious injury for one person.

The full list of aids and adaptations in *table 4.36* is useful for identifying the range of aids and adaptations available for people with learning disabilities, as well as demonstrating their probable under provision. Only 4.3% had special kitchen aids in place for example, yet burns and scalds from the use of kitchen equipment (electric kettle or iron) was also highlighted in this PhD research project.

Aids such as vibrating smoke/fire alert pillow, temperature controlled hot water, and kitchen safety equipment are potentially quite important, as they are straightforward and cost-effective interventions for the prevention/minimisation of injuries, falls and accidents. It would be of interest to better understand the reasons for so little being used, and to try to raise awareness of their availability, and promote their use for adults with learning disabilities in the future.

5.6.2. Risk Assessments

Individual or individualised risk assessments are an important feature of supported living and residential care to maintain the well-being and safety of adults with learning disabilities in their homes and community. However, only 60.1% of the paid carers (of 228 of the adults with learning disabilities) reported that individual risk assessment/s had been carried out for the person with learning disabilities they care for/support at any time *and* updated/reviewed in the previous 12 months. This finding corresponds with only 57.9% of the paid carers reporting that they had received training on risk assessments at any time. As for aids and adaptations, there appears to be an under use of the measures/steps available to

help prevent injuries. Only 9.2% (16 out of 228) of the adults with learning disabilities with a corresponding paid carer respondent had been individually assessed for falls risk, despite the high incidence of falls and fall injuries amongst people with learning disabilities. That the risk of falling had been formally considered by paid carers for some demonstrates that it is possible to do this, and this is an area requiring further exploration, development of instruments, training, and research to evaluate such interventions. There may well be a need for paid carers to receive mandatory/compulsory training on risk assessments.

5.6.3. Recording and Reporting Incidents

There was variation in both the paid carers' awareness of procedures for recording and reporting injury incidents within their employer organisation, and actual recording and reporting procedures between organisations. For example, some paid carers were not familiar with an incident-recording procedure, or with who is notified when an injury occurs within their organisation (e.g. line manager or head office personnel). Most paid carers (66.7%) reported that an injury incident form was completed for organisational use only, with no in-house/on-site recording of injury incidents formalised also as part of this procedure, to ensure effective communication of injury incidents between the team of care/support staff on-site as well as at organisational level. This potentially reduces the likelihood of patterns of repeated injuries or accidents being identified for the same service-user, or groups of users sharing a home/service, and could be rectified.

Whilst accommodation type/living arrangement was not found to be a predictive risk factor for any of the five outcomes regarding injury, falls and other accidents in this PhD research project, more consistent recording and reporting of injury incidents is suggested to increase awareness and further promote the safety and well-being of people with learning disabilities who live with paid support. The content of injury incident forms/reports were not investigated in this PhD research project, but previous research by the Donald Beasley Institute (2002), which was reliant on collecting injury incident data from care/staff reports, did report problems with this, in terms of incomplete data and inconsistency. More consistent recording/reporting would be beneficial for service audits of organisations providing care/support to people with learning disabilities, as well as collaborative research with service providers in the future.

5.7. Carers' Injuries

This PhD research project has also determined for the first time, the incidence, types and causes of injuries experienced by carers of adults with learning disabilities over a 12-month period. A previous study by Hill-Smith et al. (2002) reported that 3.5% of mothers and 2.3% of fathers (unpaid carers) of people with learning disabilities had died as a result of accidental injury, but no other study has investigated non-fatal injuries in paid and unpaid carers.

The group of carers who participated in this PhD had actually experiences fewer injuries than the rest of the population: 9.8% compared with 12.2% of adults in the SHS 2003 general population who live in the same Greater Glasgow geographical region (standardised injury ratio = 0.81). The carers were less likely to have experienced certain types of injuries, including cuts/grazes, burns/scalds, and swelling/tenderness. This might reflect the responsibility of their caring/support role. Conversely however, regarding causes of injuries, they were significantly more likely to experience injury from another person, a feature of their care for people with problem behaviours, although they were less likely to experience injury as a result of using a tool, implement, or equipment. Carers may be less likely to use industrial tools, implements or equipment in a work setting e.g. factory, but they may use equipment such as a wheelchair or hoist with the persons with learning disabilities they care for/support. Injuries regarding carer's misuse of equipment were reported earlier for the adults with learning disabilities, but no injuries regarding misuse of equipment was reported for the carers. Due to the earlier finding for the adults with learning disabilities however, adequate provision and training in the use of care/support equipment appears to be indicated.

5.7.1. Carer Error and Misuse of Equipment

Following on from the last paragraph, carer error and misuse of equipment was not reported for the carer sample on injuries, but 1.2% of the adults with learning disabilities experienced at least one injury in the 12-month period as a result of carer error/misuse of equipment. This includes injury as a result of carer misuse of equipment (e.g. the near drowning to the carer stopping on a canal path and failing to apply wheelchair brakes), poisoning as a result of a drug administration error, hot shower water scalds/burns whilst his unpaid carer (mother) was assisting him to shower at home. This demonstrates the importance of carers being included in future measures/interventions to prevent/minimise injuries in people with learning disabilities in the future. Serious (e.g. burns/scalds from

bathing) and fatal (e.g. drowning) injuries caused by carers themselves would most likely be even more devastating for the carers.

5.7.2. Injury from Harm

Carers were significantly more likely to experience injury from others when compared with the general population, highlighting the risk of injury as a result of caring for/supporting someone who has problem behaviour/s e.g. physical aggression (Allen, 1999). Of the carers who experienced injury from the harmful action/s of another person mostly this was from a person with learning disabilities they care for/support. The figure is not dissimilar to that for the adults with learning disabilities who experienced at least one harmful injury from another person. So, carers of adults with learning disabilities are at a significantly increased risk of harmful injury in their caring/support role when compared with the general population, but are not at a significantly increased risk of harmful injury when compared with the adults with learning disabilities they support. This highlights the importance of problem behaviour/s management in care/support settings.

5.7.3. Falls and Fractures

Falls were the most common cause of injury for both the carers and the general population, with no significant difference between the samples. Unpaid carers however, were significantly more likely to experience fall injury when compared with paid carers and to sustain fractures. This finding most likely demonstrates the different demographics between the two groups of carers, with unpaid carers being more likely to be older women (mothers) at an increased risk of e.g. osteoporosis.

As anticipated, the pattern of types and causes of injuries differed between the carers and the people with learning disabilities they care for, despite their shared environment for at least part of the day.

5.7.4. Contributory Factors

Most carers who had experienced at least one injury were also able to identify a hazard/factor which had contributed to their injury incident; the most commonly reported were indoor and outdoor environmental factors, contact sports, and physical health factors. As for the people with learning disabilities, stairs/steps were the most commonly reported environmental contributory factor for the carers. However, for the carers, it was indoor steps, whilst for the people with learning disabilities it was outdoor steps. This is an interesting finding, considering adults with learning disabilities and their carers share the

same environment, but the risk of stairs/steps differs between them when they are in/outdoors.

5.8. Building on the Previous Literature on People with Learning Disabilities: What this PhD Adds

This PhD research project is the first of its kind internationally to determine the incidence, types and causes of injury experienced by community-based adults with learning disabilities, and to identify predictive risk factors for injuries, falls and other accidents. Previous research has identified mainly associated (cross-sectional) risk factors for injuries/falls/other accidents in people with learning disabilities (Hsieh et al., 2001; Sherrard et al., 2001a; Sherrard et al., 2002; Grant et al., 2001; Wagemans et al., 2006; Chiba et al., 2009), but most of these studies have been limited by their restricted samples of nursing home residents with learning disabilities (Hsieh et al., 2001; Chiba et al., 2009) or adults with learning disabilities who are users of a specific service/provider (Grant et al., 2001; Wagemans et al., 2006). Of these studies however, two do stand out as being more relevant to the research contained with this thesis: Hsieh et al. (2001) who did investigate predictive risk factors for incident injury, fall injury and accidental injury other than falls; and Sherrard et al. (2001a; 2002) who were the first internationally to determine the self/proxy reported incidence, types and causes of fatal and non-fatal injuries in community-based children/young adults with learning disabilities, and report associated risk factors for injury in this population. Sherrard et al. (2001a) also demonstrated that most injuries experienced by children/young adults with learning disabilities occurred at home (unlike the general population); 53.6% (75) of the total number of injury incidents (n = 140) `in this PhD research project also occurred at home. These two studies in particular informed the development of this research project for this PhD, and allow for some comparison.

Sherrard et al. (2001a) has shown the standardised non-fatal/fatal injury ratio for children and young adults with learning disabilities to be 2. This research contained within this thesis has demonstrated that adults with learning disabilities (aged 18 – 64 years) also experience a higher incidence of non-fatal injury when compared with adults without learning disabilities in the general population, whereby the standardised injury ratio equals 1.78 (CI 1.44 – 2.17). The incidence of injuries in children and adults with learning disabilities therefore, is a major concern.

Hsieh et al. (2001) found that 11% (30 people) of 268 nursing home residents with learning disabilities had sustained injuries in a 12-month period, 50% (15) of which had been caused by falls. In this PhD research project, 22.1% (113 people) had experienced at least one injury in a 12-month period, 54.9% (62) had been caused by falls. 8.0% (41 out of 511 people) of the adults with learning disabilities in this PhD research project were aged 65 years and over, 21.9% (9) of whom had experienced at least one injury in the 12-month period, 66.7% (6) had been caused by falls. The incidence of injuries of injuries for this community-based sample of adults with learning disabilities therefore, was double that found for nursing home residents with learning disabilities in the Hsieh et al. (2001) study.

Hsieh et al. (2001a) identified three predictive risk factors for incident injury, which were epileptic seizure frequency (more than monthly), destructive behaviour, and antipsychotic drugs. They also identified three predictive risk factors for incident fall injury, which were epileptic seizure frequency (less than monthly), being ambulatory, and aged 70 years or over; and three predictive risk factors for incident accidental injury (other than fall injury), which were adaptive behaviour, good physical health, and destructive behaviour. Sherrard et al. (2002) also found the presence of epilepsy, psychopathology (problem behaviours), and an overly sociable temperament to be associated factors for incident injury; and that being blind, deaf, and immobile reduced risk. Like Hsieh et al. (2001) and Sherrard et al. (2002), the author of this thesis found that a person's gender and their level of learning disabilities were not risk factors for any of the outcomes investigated, but it was the presence of epilepsy (Sherrard et al., 2002), not epileptic seizure frequency (Hsieh et al., 2001), which was identified as an independently predictive risk factor for incident injury, and autism was identified as an independently protective factor. The presence of epilepsy was also identified as an independently predictive risk factor for fall injury (seizure related falls included). Number of drugs, rather than antipsychotic drugs, were investigated in this PhD research project, and problem behaviours rather than specific types of problem behaviour, to increase the statistical power in the cohort. Physical health status was not included. Visual impairment, hearing impairment, and impaired/mobility were not found in this PhD research project to be either predictive or protective factors for any of the five outcomes, and no predictive/protective factors at all were found for incident accidental injury (other than fall injury). Hsieh et al. (2001) found age 70 years and over to be a predictive risk factor for incident fall injury using age categories in their analyses, whereby age was not found to be a predictive/protective factor for any of the outcomes using numeric age in the analyses in this PhD research project and the Sherrard et al. (2002) study. The results from this PhD research project build on the work of Hsieh et al. (2001a)

and Sherrard et al. (2001a; 2002), but future studies should give much consideration to the factors being investigated, age, epilepsy and problem behaviour/s in particular; and include antipsychotic drugs.

This PhD research project has identified autism as an independently protective factor for incident injury of adults with learning disabilities for the first time; as well as urinary incontinence as a predictive risk factor for incident fall injury (excluding seizure-related fall injury) and repeated falls with or without injury, and Down syndrome as an independently protective factor for the same two fall outcomes. This demonstrates the importance of investigating incident fall injury including/excluding seizure-related fall injury in people with learning disabilities, given the much higher prevalence of epilepsy in this group/population (Lhatoo et al., 2001).

Poor balance/coordination was found in this PhD research project to be associated with repeated falls with or without injury. Previous research by Hale et al. (2007) has demonstrated that routine physiotherapy tests to assess balance capabilities are unsuitable for adults with profound learning disabilities, mainly because they are unable to understand what is required of them. More recently however, Chiba et al. (2009) found the Tinetti assessment tool [Levine et al., 2001], which is used to assess gait and balance in older adults without learning disabilities in the general population, to also be a valid a reliable tool for detecting fall risk in older/adults with learning disabilities. Future research will continue to draw on existing measures (and interventions) which are routinely used with older/adults in the general population, conducting pilot studies to ensure they are suitable for use with people with learning disabilities, or require modification, as well as develop new measures (and interventions) for this group/population.

Konarski et al. (2005) has developed a promising risk of injury assessment tool for use with adults with learning disabilities, but so far this tool has only been tested with adults with learning disabilities in an institutional setting, and informed by risk factors only identified for the same restricted sample. Further development of this tool, or a similar tool, could be a future direction of the research contained within this thesis on community-based adults with learning disabilities.

Previous research has reported higher rates and different patterns of mortality in people with learning disabilities in relation to fatal injuries (Dupont et al., 1987; Strauss et al., 1998; Community Services Commission, 2001; Sherrard et al 2001a; and Durvasula et al.,

2002). Sherrard et al. (2001a) found the standardised injury mortality ratio for children and young adults with learning disabilities to be 8, when compared with children/young adults without learning disabilities in the general population living in the same geographical region. Fatal injuries were not investigated in this PhD research project. The severity of injuries was not fully explored either, although two incidences of near fatal injury were identified (one instance of choking, and one instance of near drowning). Future studies on injuries in people with learning disabilities should also try and investigate fatal and non-fatal injuries wherever possible, to gain a full picture of the severity of the problem of injuries in this group/population.

Previous literature on increased risk of fracture for people with learning disabilities was included in the Introduction chapter of this thesis because it is of related interest. Fractures were the fourth most common type of injury identified, experienced by 3.1% (16 people) of the adults with learning disabilities in this PhD research project. Fracture risk however, was not investigated. Future research should also consider fracture risk in relation to incident injury, falls and other accidents, as not enough is known about risk factors previously identified for fractures (e.g. osteoporosis) in relation to falls and other accidents in this group/population (Schrager et al., 2007).

Throughout this PhD, the hazards people with learning disabilities navigate through on a frequent and sometimes daily basis were prominent, and future research would usefully consider aids, adaptations, and the risk assessment processes. Interventions to reduce the injuries in this population are likely to require a multi-component approach, addressing these systems factors, and well as individual factors such as muscle strength, balance and coordination exercises, epilepsy management and possibly Vitamin D, tailored on an individual basis.

5.9. Building on Previous Literature Older Adults in the General Population: What this PhD Adds

Previous research on injuries and falls in older adults in the general population is well-developed, given that 28% to 35% of older adults over 64 years of age fall each year, and fall injuries are a major concern (World Health Organization, 2008a) (this compares with 40.1% of adults with learning disabilities in this PhD research project); and researchers in this area are currently working towards a consensus methodology in this field (e.g. the Prevention of Falls Network Europe) (Lord et al., 2007). This literature has informed the

development of this PhD research project (e.g. defining falls), and highlights the need for the researchers who are concerned with injuries, falls and other accidents in people with learning disabilities to also develop consensus in their methodology. The fall definition used in this PhD research project was, 'an event that results in a person coming to rest inadvertently on the ground or other level' (adapted from O'Neill et al., 1996), which is much the same as the current fall definition recommended by Lamb et al. (2005) (published after data collection for this PhD research project had commenced), which is 'an unexpected event in which the participants come to rest on the ground, floor, or other lower level'. In this PhD research project, a lay perspective of a fall was also used, which is also recommended (Lamb et al., 2005).

Also drawing from the literature on injuries and falls in older adults, eight T1 and four T2 factors were investigated in this PhD research project for injury/fall risk, because they were experienced more commonly by adults with learning disabilities (when compared with the general population), and/or had been identified as risk factors for falls in older adults without learning disabilities in the general population. These factors were: age, gender, area deprivation (socioeconomic status), visual impairment, urinary incontinence, foot/toe deformity (foot problems), body mass index (weight), and number of prescribed drugs as T1 (predictive) factors; and poor balance, sedentary behaviour, fear of falling (self-efficacy), and poorly fitting shoes as T2 (associative) factors. Urinary incontinence was identified in this PhD research project as being an independently predictive factor for both incident fall injury (excluding epilepsy seizure-related falls) and repeated falls (three or more falls) with or without injury. None of these other factors however, were identified as being either predictive/protective or associated factors for any of the five outcomes regarding injuries, falls and other accidents in this PhD research project. Other factors identified as risk factors for falls in older adults without learning disabilities in the general population include ethnicity, diabetes, Parkinson's disease, alcohol misuse, muscle weakness, stairs/steps, depression, Alzheimer's disease, previous history of falls, and cognitive impairment (World Health Organization, 2008a). These were not included in this PhD, in view of the low prevalence of these problems in people with learning disabilities, or measurement difficulties. Future studies might attempt to explore these further, particularly as stairs/steps were perceived by the adults with learning disabilities (and their carers) as being a contributory factor/hazard, and previous history of fractures has a bearing on fracture risk.

Previous studies have also reported older age and visual impairment as being risk factors for fall injury (Hsieh et al., 2001; Wagemans et al., 2006) and repeated falls (Wagemans et al., 2006) in adults with learning disabilities, but these studies have used restricted samples and their results cannot be generalised. Older age and visual impairment were not found to be risk factor for injuries, falls and other accidents for population/community-based adults with learning disabilities in this PhD research project; nor were they found to be risk factors for incident injury in population/community-based children/young adults with learning disabilities in the Sherrard et al. (2002) study; where being blind, deaf and immobile were actually found to reduce risk.

The reason why people with learning disabilities do not share the same risk factors for injuries, falls and fall injuries as older adults without learning disabilities in the general population (despite these factors also occurring more commonly in people with learning disabilities), is probably simple; older adults in the general population are more likely to develop these problems (factors) later on in life as part of the ageing process, whereas people with learning disabilities are more likely to have these problems/factors throughout their life, from birth. A person without learning disabilities in the general population is more likely to have normal vision for example, and only develop problems with their eyesight later on as part of ageing, whereas a person with learning disabilities who has visual impairment is more likely to have had problems with their eyesight since birth. The results contained within this PhD thesis demonstrate that injuries and falls (and other accidents) are also a major concern for adults with learning disabilities, as they are for older adults without learning disabilities in the general population, but for different reasons. Together with the results reported by Sherrard et al. (2001a), these findings also demonstrate that injuries, falls and other accidents are a problem for people with learning disabilities across all ages.

Whether older adults with learning disabilities (aged 65 years and over) develop a different pattern of injury and falls and risk factors for injury and/or falls due to ageing as well, is difficult to establish in this group/population due to existing health inequalities (lower life expectancy) (Patja et al., 2003; Cooper et al., 2004; Graham, 2004), with fewer adults with learning disabilities in population-based samples being 65 years of age and over compared with the general population. Only 8.0% (41 out of 511) of the adults with learning disabilities in this PhD research project were aged 65 years or over. Of these older adults with learning disabilities, 21.9% (9 out of 41) had experienced injury in the 12-month period, of which 66.7% (6) had been caused by falls. Future research should also work

towards conducting injury and falls research on larger samples of older adults with learning disabilities to investigate this. The health and well-being of older adults with learning disabilities is also a growing concern, as gaps in health equality (including life expectancy) are increasingly being addressed and closing.

5.10. Strengths and Limitations of this PhD Research Project

This PhD research project was built on to a larger longitudinal study at T2, two-year follow up. This enabled the author to conduct this research with a population-based and community-based cohort of adults with learning disabilities. The large size of the cohort, and the high cohort retention (63.9%, 511 people) by T2, is a strength of this PhD research project (cohort retention is known to be typically lower for adults with learning disabilities than for the general population) (Wadsworth et al., 1992; Maughan et al., 1999; Richards et al., 2001). The author was also able to utilise T1 data, which was based on a comprehensive health check, for the analyses identifying independently predictive and protective factors for injuries, falls and other accidents of adults with learning disabilities. An additional strength is that the comparison data was similarly and contemporaneously collected for adults in the general population in the same geographical region in the SHS 2003 (Scottish Executive, 2005). Given that it is a community-based sample including both deprived and affluent areas, and with a high participation rate, the findings are likely to be generalisable to other areas in developed countries.

Limitations of this PhD research project include that data collected on the number, types and causes of injuries were reliant on the recall of adults with learning disabilities and their carers and relatives, and with regards to paid carers, also their records and incident forms. From their research with children and young adults with learning disabilities, Sherrard et al. (2001b) reported that whilst their own data collection was highly specific (99.2%; CI=95.6-99.9%), its sensitivity was less so (57.5%; CI= 44.1-69.9%), and resulted in not all injuries being identified. There may well be the same issue with this PhD, in which case the results may present an underestimate of the scale of the problem with adults with learning disabilities.. The comparable SHS 2003 data were also reliant on recall.

Self-report research which is reliant on the recall of persons with learning disabilities, and their carers by proxy, can be problematic with regards to e.g. acquiescence and comprehension (Finlay et al., 2001). The questionnaire used in this research project was completed during a face-to-face interview, whereby the researchers using various

interviewing techniques (e.g. anchoring, and asking the same question in different ways) to assist recall as much as possible, and check the person's understanding. Prompting participants to anchor events over a particular time period to another more memorable event/occasion, such as a birthday celebration or a holiday, for example, helps guard against participants over-reporting injuries, falls and other accidents that may have occurred before the 12-month period.

The main instrument for self-report/proxy data collection in this PhD research project was a questionnaire which was developed and administered by three different researchers (including the author). The questionnaire was piloted, with regards to face and content validity, but it was not tested for inter-rater reliability until recently (November 2010). This was an oversight, although the Kappa test scores equalling 1.00 do demonstrate excellent inter-rater and test-rest reliability when subsequently tested.

One other questionnaire in the study was purpose designed. This collected information on age, gender, occupation, type of accommodation and post-code.

This PhD research project was built on to a larger study, which brought the advantages of the longitudinal design, but also limited the additional measures that could be introduced, as the data being collected was collected during the last 30 minutes of a typical interview lasting 1 hour and 40 minutes; and in keeping with the nature and time frame of these interviews, no other methods of data collection were used, such as physical assessment or e.g. injury/falls diaries.

For each of the 5 injury/falls outcomes, 31 variables were considered (22 measured at T1 and 9 at T2). This introduces the possibility of a type I statistical error, where variables are considered to be individually related to the outcome when in fact the finding is purely one of chance association. However, the study was necessarily exploratory, in view of the considerable limitations in the existing literature, and hence this approach is justified. The independent variables retained within the final regression models can also be clinically interpreted, suggesting plausibility for the models. However, it is important that this limitation is fully recognised so that undue claims are not made of the research, and in full recognition that the findings within this study need to be replicated, and that further hypothesis based analyses are required in future studies.

Additionally, nine of the factors explored for associations were only cross-sectional data collected at T2, limiting any assumptions that might otherwise possibly be drawn regarding the direction of the cause and effect relationship, should one exist.

The comparison of carer data with both the people with learning disabilities they care for, and with the general population may be limited by differing age ranges and gender distribution of these groups. Given the sample size, it was not possible to address this through comparisons which were age and gender matched. For the comparisons between the people with learning disabilities and the general population, there is a similar issue, although people aged 65 and over were not included in the main comparisons which addresses the greatest difference.

Chapter Summary

The results contained within this thesis should be generalisable to other people with learning disabilities in high-income countries. People with learning disabilities have a high incidence of injuries, higher than for the general population, and have a different pattern of type and cause of injury.

This PhD research project has also identified for the first time, risk factors for injuries, falls and other accidents in community-based adults with learning disabilities. It has used a robust methodology to report the rates of injuries accidents and falls in this population, improving upon the existing literature. It also investigated injuries experienced by carers. In this discussion, the study findings have been compared with the previous literature, as far as this is possible. The discussion has considered what this PhD adds to our existing knowledge. It has interpreted the findings so that the implications of them are understood, and to inform the actions to follow, in terms of working towards reducing injuries through changes in practice, and the need for future research to support this agenda.

The PhD findings have implications with regards to building our knowledge-base through future research, and raising our awareness of this high incidence problem for people with learning disabilities. The differences between people with learning disabilities and the general population, in terms of age ranges most affected, types and causes of injury, and the predictive and associated factors and likely contributory hazards and environments, highlight that the needs of the population with learning disabilities need to be specifically addressed and cannot rely on strategies and policy determined for the general population.

Should the latter continue to be the case – as it is now – the current health inequality gap between people with learning disabilities and the rest of the population is likely to widen.

This PhD does have some limitations, but nonetheless, contributes important new knowledge to a research area that has received surprisingly little attention thus far. The implications of these findings for future policy and practise, research and education will be considered in the next chapter, which is the Conclusion.

CHAPTER 6:
CONCLUSION

6.1. Conclusion

This PhD research project was built on to a larger longitudinal study, and a programme of research aimed at improving the health and well-being of adults/people with learning disabilities. By determining the incidence, types and causes of injury experienced by adults with learning disabilities (compared with the general population), and identifying risk factors for injuries, falls and other accidents, its findings are a further step towards addressing and reducing health inequalities of people with learning disabilities. These findings also establish the first two steps of the public health four key steps approach to injury prevention (Mercy et al., 1993). The next step will be to design, pilot-test, and evaluate interventions for injury prevention; before implementing the most promising interventions on a broader scale.

The findings from this PhD research project will now be concluded in this chapter, in relation to their implications for policy and practise, future research, and education.

6.1.1. Policy and Practise

The findings from this PhD research project demonstrate that adults with learning disabilities experience injury, falls and other accidents more commonly than adults without learning disabilities in the general population. The standardised injury ratio for adults with learning disabilities was found to be 1.63, so injuries are a major concern. Adults with learning disabilities also experience different patterns of the causes and types of injury, with the majority of injuries occurring at home (unlike the general population). These findings increase our awareness and understanding of the problem of injuries, falls and accidents in people with learning disabilities.

Unlike for adults with learning disabilities, literature on injuries and falls in older adults without learning disabilities in the general population is well developed. Between 28% and 35% of older adults (aged 64 years and over) experience falls each year (World Health Organization, 2008a), and hence the considerable attention that has been given to the topic. Several interventions and specialist teams have been developed, and reviews of trials of interventions for the prevention of falls in older adults in the general population (e.g. Chang et al., 2008) illuminate this point. In this PhD research project, falls incidence for adults with learning disabilities (aged 18 years and over) was found to be 40.1% (205 people). Adults with learning disabilities therefore, experience falls even more commonly than older adults without learning disabilities in the general population. As yet there has

been no investment in the development of interventions or teams to support these health, well-being and safety needs. This is needed, and given the differing predictive risk factors, it is likely that interventions will have to be designed specifically for adults with learning disabilities; as whilst we will be able to draw on the evidence base and existing models of care for falls prevention in older adults, they will have to be adapted for use with adults with learning disabilities.

Adults with learning disabilities require support to live safe and healthy lives, so the involvement of their carers in strategies and interventions to prevent/minimise injuries will also be key; 90.0% (460) of the adults with learning disabilities in this PhD research project were supported by a carer during their research interview, and 47.2% (241) did not have capacity to consent to take part on their own. These strategies/interventions will also be likely to include for example, carer training/support to prevent injuries to people with learning disabilities through the misuse of equipment such as wheelchairs or hoists, and more effective problem behaviour management to prevent injury to carers. Carers in this PhD research project were found to experience injuries less commonly when compared with the general population (standardised injury ratio = 0.81), but they were also found to experience harmful injury from another person more commonly ($p = 0.048$) as a result of their caring/support role.

6.1.2. Future Research

This is the first research project of its kind internationally to determine the magnitude and characteristics of injuries, falls and other accidents in the population of adults with learning disabilities, and identify predictive risk factors. As the first of its kind, it was necessarily exploratory. It provides infrastructure for further hypothesis-based secondary analysis.

The research contained within this thesis makes a significant contribution to our awareness and understanding of the phenomenon of injuries, falls and other accidents in the population of adults with learning disabilities, which was an under-researched area. It is important to consider the implications of what this research does and still does not add to our understanding of injuries, falls and other accidents in people with learning disabilities in terms of recommendations for future research. These recommendations for future research are:

- Future prospective study of injuries, falls and other accidents in the population of learning disabilities, also paying attention to fatal injury, severity of injury and

consequences of injury to gain a fuller picture of the severity and cost of injuries experienced by people with learning disabilities.

- Further study on fracture risk (e.g. osteoporosis) in relation to injuries from unintentional injuries from falls and other accidents.
- Further study on injuries, falls and other accidents in older adults with learning disabilities, utilising larger samples of older adults with learning disabilities if possible.
- An emphasis on risk of injury and risk of falling assessment, through the development of risk assessment tools specifically for use with people with learning disabilities, and the identification of more predictive risk factors (including the identification of possible sets of common/shared risk factors e.g. urinary incontinence?). Future studies investigating risk factors for example, should include the factors not tested in this PhD research project (e.g. psychotropic drugs, and stairs/steps which were perceived by the carers as being contributory factors), and test the predictive quality of the associated factors identified in this PhD research project (e.g. poor balance/coordination) in studies of longitudinal design.
- Develop more valid and reliable methods for future studies on injuries, falls and other accidents of people with learning disabilities (which are suitable for use with people with learning disabilities), and, as in the case of researchers in the field of falls in older adults, ensure researchers are working towards a consensus methodology.
- Further study to explore the possible reasons why adults with learning disabilities and autism are less likely to experience incident injury, and why adults with Down syndrome are less likely to experience incident fall injury (excluding seizure related) and repeated falls (three or more falls).
- Collaborative research with providers of support living to adults with learning disabilities, and their staff, to develop more consistent incident recording and reporting procedures for the purposes of research and service audits; to promote more effective procedures for monitoring and maintaining the health and well-being of people with learning disabilities who live with paid support.
- A multi-disciplinary team working approach to pilot-testing interventions to prevent/minimise injuries, falls and other accidents experienced by adults with learning disabilities, including for example, occupational therapists with regards to aids and adaptations, physiotherapists with regards to poor balance/coordination, and psychologists/psychiatrists with regards to epilepsy and problem behaviour management.

6.1.3. Education

As mentioned in the Introduction chapter of this thesis, the past few decades has seen a shift in the provision of health and residential services for adults with learning disabilities, from institutionalised to community-based care/support. This has led to a number of epidemiological studies (e.g. Howells et al., 1986; Beange et al., 1995; Smiley et al., 2007) highlighting the different patterns of health of people with learning disabilities compared with the general population, thus their different health needs. Raising the awareness of the different health needs of people with learning disabilities amongst community-based health care professionals, parents/relatives of people with learning disabilities, and supported living/residential care service providers and their staff is recognised as being key to ensuring the particular health needs of people with learning disabilities are being met (e.g. Melville et al., 2005; 2006). The findings from this PhD research project add to our understanding of the different patterns of health of people with learning disabilities, thus educating community-based health care professionals (including specialist learning disabilities teams), parents and other main carer relatives, and supported living/residential care service providers and their staff will also be important in the wider dissemination of these results. This is likely to include: educating multi-disciplinary health care professionals (including specialist teams) on the importance of more effective provision of aids and adaptations, risk/assessment (including a working knowledge of risk factors), epilepsy management, and problem behaviour management; additional training for carers on the safe use of aids and adaptations, and responses to problem behaviour/s; and the recommendation that paid carers receive mandatory training on individualised risk assessment, as well as the recommendation for more consistent recording and reporting of incidents across providers of supported living services and residential care.

And finally, bearing in mind that older adults with learning disabilities may find themselves living in generic care services (nursing homes or long-term hospital care for older adults), increasing the awareness of the higher incidence and different pattern of injury and falls of people with learning disabilities amongst health care professionals and researchers working with older adults will also be important.

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APPENDICES

Appendix 1: Risk of Injury Assessment Questions Extracted from Konarski et al. (2005)

1. Has the person experienced an episode of injury in the past 12 month? (3 points)
2. Can the person walk at all? (15 points)
3. Is the person presently taking antipsychotic medication? (10 points)
4. Does the person presently have a psychiatric diagnosis? (5 points)
5. Does the person exhibit any of the following behaviour disorders? (Destroys property, disrupts activities, teases, runs away, pica, aggression, abusive to others, resists supervision, steals, self-injurious behaviour) (2 points per behaviour)
6. What are the effects of the person's behaviour disorders? (Movement to less restrictive setting prevented, behavioural programming required, environmental arrangements required, physical intervention needed, one-to-one supervision required) (2 points per effect)
7. Has the person had a simple seizure, tonic seizure, or lost consciousness due to a seizure in the last 12 months? (5 points)
8. Does the person have a cardiovascular, neurological, gastrointestinal, or respiratory condition? (5 points)

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INJURIES, ACCIDENTS AND FALLS IN ADULTS WITH LEARNING DISABILITIES

PARTICIPANT INFORMATION SHEET

We would like to invite you (and someone who supports you) to take part further in a research project on injuries, accidents and falls in adults with learning disabilities. This information sheet tells you about the project, and the same information is also available on audio cassette tape.

Before you decide whether or not you wish to take part, it is important to understand why the research is being done and what it will involve. Please take time to read through the following information and talk about it with others if you wish.

If there is anything that you are not sure about, or would like more information on, then please do not hesitate to contact us on 0141 211 0691. If you would like a copy of this information on tape, please contact us on 0141 211 0691.

Why are you studying injuries, accidents and falls in adults with learning disabilities?

Young people with learning disabilities are known to have more injuries, and different types of injuries, than other young people in the general population, but little is known about how often adults with learning disabilities are injured, and what types of injuries adults with learning disabilities have. We want to know more about injuries, accidents and falls in adults with learning disabilities. This will help work towards reducing these in the future.

What will this research project find out?

This research project will find out how often adults with learning disabilities are injured, and what types of injuries adults with learning disabilities have.

This research project will also find out the effect injuries have on the lives of adults with learning disabilities and their families and/or support staff. It will also try to find ways of reducing injuries in adults with learning disabilities in the future.

Why do you want me to take part in this project?

You have already taken part in a research project on the incidence of mental health and mental ill health of adults with learning disabilities. As part of that project, you answered some questions on things that have happened to you within a 12-month period, which included some questions about injuries, accidents and falls. That information is already helping us to learn more about how often adults with learning disabilities are injured, and the types of injuries experienced.

You are being asked to take part in this new research project, because you told us that you had experienced either more than one injury, or a serious injury, within a 12-month period. We think that you will be able to help us learn more about the effects of injuries on the lives of adults with learning disabilities and their families and/or support staff.

What will the project involve?

If you decide to take part in this research project, Janet Finlayson (Research Assistant) will visit you at home again, to talk about injuries, accidents, or falls. What you want to say about your experiences will be recorded on audio cassette tape, to allow Janet to give you her full attention and listen. If it is okay with you, at the same time, Janet will also talk to your relative or your support worker about your injuries, accidents, or falls. What they want to say will also be recorded on audio cassette tape.

Same as before, Janet will arrange to visit on a date and time that is suitable for you. Janet will also explain the research project to you and answer any questions.

This research interview will mainly involve Janet listening to what you have to say about injuries, accidents and falls, and will only take as long as you need. You can choose to stop the interview, or withdraw from the project, at any time.

Will I have to give my consent?

If you agree to take part in this new research project, there will be a consent form for you to sign.

What will happen to the information I provide on tape?

The information that you provide on tape will be treated in the strictest confidence by the research team. No one else will hear the tape. The information will be copied on to paper and then entered on to a computer database. The research team will make sure that the information is kept safe and secure at all times. The Data Protection Act will be adhered to at all times.

Will the research team need to look at my case notes?

No. This research project only concerns personal accounts of injuries, accidents and falls from adults with learning disabilities and their families and/or support staff. No medical or case notes will be reviewed by the research team.

What will happen if I refuse to take part?

You do not have to take part in this research project if you do not want to. It is your choice. You can ask as many questions as you like about the project and take as long as you need to decide whether you want to take part or not. If you agree to take part, you are still free to withdraw (stop) at any time and don't have to say why. If you do not agree to take part, then no interview will be carried out. A decision not to take part, or to withdraw, will not affect your future health care in any way.

How has the project been funded?

The research project has been funded by a grant from The Baily Thomas Charitable Foundation.

Has ethical approval been granted for this project?

Yes. This project has been ethically approved by the Multi-Centre Research Ethics Committee for Scotland.

What will happen to the results of this project?

We will post information about the findings of this research project to everyone who took part, in 2007. Findings from this project will also be given to local and national health and social care organisations for adults with learning disabilities. The research findings will be written into reports, which will be published. It will not be possible to identify any of the individuals who take part in this study from the reports, as all information will be anonymised.

What will happen if I take part and then feel unhappy about it, or the way I have been treated?

If at any time during the study you feel unhappy about it, or the way you are being treated, then we will stop. We do not expect to make you unhappy in any way, but if we do, you should complain. You should complain to NHS Greater Glasgow Primary Care Division. We are obliged to inform you that if this research study harms you, there are no special compensation arrangements. If you are harmed by

someone's negligence, then you may have grounds for a legal action but the research team cannot compensate you for this.

How can I find out more about this project?

Please feel free to contact Janet Finlayson, or any of the research team, at any time during any stage of the project, to discuss any aspects of the project, or ask questions. Janet will be happy to answer your questions over the telephone, or if you prefer, she will visit you at home in person.

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The Research Team

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Professor Jillian Morrison, Professor of General Practice, University of Glasgow
Miss Janet Finlayson, Research Assistant, University of Glasgow

Thank you for taking the time to read this information sheet.

Appendix 3: Staff Project Information Sheet

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Injuries, Accidents and Falls in Adults with Learning Disabilities

SUPPORT WORKER INFORMATION SHEET

We would like to invite the person you support and you to take part further in a research project on injuries, accidents and falls in adults with learning disabilities. This information sheet tells you about the project, and the same information is also available on audio cassette tape.

Before you decide whether or not you wish the person you support and you to take part, it is important to understand why the research is being done and what it will involve. Please take time to read through the following information and discuss it with others if you wish.

If there is anything that is not clear, that you would like more information on, or if you want to request a copy of the information on tape, then please do not hesitate to contact us on 0141 211 0691.

Why are you studying injuries, accidents and falls in adults with learning disabilities?

Young people with learning disabilities are known to have more injuries, and different types of injuries, than other young people in the general population, but little is known about how often adults with learning disabilities are injured, and what types of injuries adults with learning disabilities have. We want to know more about injuries, accidents and falls in adults with learning disabilities, to help work towards reducing these in the future.

What will this research project find out?

This research project will find out how often adults with learning disabilities are injured, and what types of injuries adults with learning disabilities have.

This research project will also find out about what effects injuries have on the lives of adults with learning disabilities and their support staff and/or families, and will try to find ways of reducing injuries in adults with learning disabilities in the future.

Why do you want the person I support and I to take part in this project?

The person you support and you have already taken part in a research project on the incidence of mental health and mental ill health of adults with learning disabilities. As part of that project, the person you support and you answered some questions on the life events of the person within a 12-month period, which included some questions about injuries, accidents and falls. That information is already helping us to learn more about how often adults with learning disabilities are injured, and the types of injuries experienced.

The person you support and you are being asked to take part in this new research project, because you told us that the person had experienced either more than one injury, or a serious injury, within a 12-month period. We think that the person you support and you will be able to help us learn more about the effects of injuries on the lives of adults with learning disabilities and their support staff and/or families.

What will the project involve?

If the person you support and you agree to take part in this research project, Janet Finlayson (Research Assistant) will visit you at the person's home again, to talk about injuries, accidents and falls. What the person you support and you want to say about your experiences will be recorded on audio cassette tape, to allow Janet to give the person you support and you her full attention and listen.

Same as before, Janet will only arrange to visit on a date and time that is convenient for the person you support and you. Janet will also explain the research project to the person you support and you, and answer any questions.

This research interview will mainly involve Janet listening to what the person you support and you have to say about injuries, accidents and falls, and will only take as long as the person you support and you need. The person you support and you can choose to stop the interview, or withdraw from the project, at any time.

What about consent?

If the person you support and you agree to take part in this new research project, then there will be a consent form for the person you support to sign. If the person you support is unable to give his/her own consent to inclusion in this project, then there will be a consent form for the person's relative to sign.

What will happen to the information?

The information that the person you support and you provide on tape will be treated in the strictest confidence by the research team. No one else will hear the tape. The information will be transcribed and then entered on to a computer database. The research team will make sure that the information is kept safe and secure at all times. The Data Protection Act will be adhered to at all times.

Will the research team need to look at the person's case notes?

No. This research project only concerns personal accounts of injuries, accidents and falls from adults with learning disabilities and their support staff and/or families. No medical or case notes will be reviewed by the research team.

What will happen if the person I support and I refuse to take part?

The person you support and you do not have to take part in this research project if you do not want to. You can ask as many questions as you like about the project and take as long as you need to decide whether or not to take part. If the person you support and you agree to take part, you are still free to withdraw at any time and without having to say why. If the person you support and you do not agree to take part, then no interview will be carried out. A decision not to take part, or to withdraw, will not affect the person's health care in any way.

How has the project been funded?

The research project has been funded by a grant from The Baily Thomas Charitable Foundation.

Has ethical approval been granted for this project?

Yes. This project has been ethically approved by the Multi-Centre Research Ethics Committee for Scotland.

What will happen to the results of this project?

We will post out information about the findings of this research project to everyone who takes part, in 2007. Findings from this project will also be given to local and national health and social care organisations for adults with learning disabilities. The research findings will be written into reports, which will be published. It will not be possible to identify any of the individuals who take part in this study from the reports, as all information will be anonymised.

How can I find out more about this project?

Please feel free to contact Janet Finlayson, or any of the research team, at any time during any stage of the project, to discuss any aspects of the project, or ask questions. Janet will be happy to answer your questions over the telephone, or if you prefer, visit you in person.

Miss Janet Finlayson
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The Research Team

Professor Sally-Ann Cooper, Professor of Learning Disabilities, University of Glasgow
Professor Jillian Morrison, Professor of General Practice, University of Glasgow
Miss Janet Finlayson, Research Assistant, University of Glasgow

Thank you for taking the time to read this information sheet.

Appendix 4: Relative Project Information Sheet

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Injuries, Accidents and Falls in Adults with Learning Disabilities

RELATIVE INFORMATION SHEET

We would like to invite your relative and you (or the staff who support your relative) to take part further in a research project on injuries, accidents and falls in adults with learning disabilities. This information sheet tells you about the project, and the same information is also available on audio cassette tape.

Before you decide whether or not you wish your relative and you (or support staff) to take part, it is important to understand why the research is being done and what it will involve. Please take time to read through the following information and discuss it with others if you wish.

If there is anything that is not clear, that you would like more information on, or if you want to request a copy of the information on tape, then please do not hesitate to contact us on 0141 211 0691.

Why are you studying injuries, accidents and falls in adults with learning disabilities?

Young people with learning disabilities are known to have more injuries, and different types of injuries, than other young people in the general population, but little is known about how often adults with learning disabilities are injured, and what types of injuries adults with learning disabilities have. We want to know more about injuries, accidents and falls in adults with learning disabilities, to help towards reducing these in the future.

What will this research project find out?

This research project will find out how often adults with learning disabilities are injured, and what types of injuries adults with learning disabilities have.

This research project will also find out about what effects injuries have on the lives of adults with learning disabilities and their families and/or support staff, and will try to find ways of reducing injuries in adults with learning disabilities in the future.

Why do you want my relative and I (or support staff) to take part in this project?

Your relative and you (or support staff) have already taken part in a research project on the incidence of mental health and mental ill health of adults with learning disabilities. As part of that project, your relative and you (or support staff) answered some questions on the life events of your relative within a 12-month period, which included some questions about injuries, accidents and falls. That information is already helping us to learn more about how often adults with learning disabilities are injured, and the types of injuries experienced.

Your relative and you (or support staff) are being asked to take part in this new research project, because your relative and you (or support staff) told us that your relative had experienced either more than one injury, or a major injury, within a 12-month period. We think that your relative and you (or support staff) will be able to help us learn more about the effects of injuries on the lives of adults with learning disabilities and their families and/or support staff.

What will the project involve?

If you agree to your relative and you (or support staff) taking part in this research project, Janet Finlayson (Research Assistant) will visit your relative and you (or support staff) at home again, to talk about injuries, accidents and falls. What your relative and you (or support staff) want to say about your relative's experiences will be recorded on audio cassette tape, to allow Janet to give your relative and you (or support staff) her full attention and listen.

Same as before, Janet will only arrange to visit on a date and time that is convenient for your relative and you (or support staff). Janet will also explain the research project to your relative and you (or support staff) and answer any questions.

This research interview will mainly involve Janet listening to what your relative and you (or support staff) have to say about injuries, accidents and falls, and will only take as long as your relative and you (or support staff) need. Your relative and you (or support staff) can choose to stop the interview, or withdraw from the project, at any time.

Do I have to give my consent?

If your relative does not have full capacity to understand this research project and decide whether or not to take part, the Adults with Incapacity Act requires that we ask you to decide whether or not to consent, on behalf of your relative.

If you agree for your relative and you (or support staff) to take part in this new research project, there will be a consent form for you to sign.

What will happen to the information?

The information that your relative and you (or support staff) provide on tape will be treated in the strictest confidence by the research team. No one else will hear the tape. The information will be transcribed and then entered on to a computer database. The research team will make sure that the information is kept safe and secure at all times. The Data Protection Act will be adhered to at all times.

Will the research team need to look at my relative's case notes?

No. This research project only concerns personal accounts of injuries, accidents and falls from adults with learning disabilities and their families and/or support staff. No medical or case notes will be reviewed by the research team.

What will happen if I do not wish my relative to take part in this project?

If you do not agree to your relative and you (or support staff) taking part, your relative and you (or support staff) will not be interviewed. You can ask as many questions as you like about this project and take as long as you need to decide whether to agree or not. If you decide to give your consent for your relative and you (or support staff) to take part, you are still free to withdraw at any time and without having to say why. A decision not to take part, or to withdraw, will not affect the future health care of your relative.

How has the project been funded?

The research project has been funded by a grant from The Baily Thomas Charitable Foundation.

Has ethical approval been granted for this project?

Yes. This project has been ethically approved by the Multi-Centre Research Ethics Committee for Scotland.

What will happen to the results of this project?

We will post out information about the findings (results) of this research project to everyone who takes part, in 2007. Findings from this project will also be given to local and national health and social care organisations for adults with learning disabilities. The research findings will be written into reports, which will be published. It will not be possible to identify any of the individuals who take part in this study from the reports, as all information will be anonymised.

How can I find out more about this project?

Please feel free to contact Janet Finlayson, or any of the research team, at any time during any stage of the project, to discuss any aspects of the project, or ask questions. Janet will be happy to answer your questions over the telephone, or if you prefer, visit you at home in person.

Miss Janet Finlayson
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Section of Psychological Medicine
Division of Community Based Sciences
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Glasgow G12 0XH

Telephone: 0141 211 0691 or 3933
Mobile: 07708487385
Email: jf96v@clinmed.gla.ac.uk

The Research Team

Professor Sally-Ann Cooper, Professor of Learning Disabilities, University of Glasgow
Professor Jillian Morrison, Professor of General Practice, University of Glasgow
Miss Janet Finlayson, Research Assistant, University of Glasgow

Thank you for taking the time to read this information sheet.

Appendix 5: Relative Consent Form

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INJURIES, ACCIDENTS AND FALLS IN ADULTS WITH LEARNING DISABILITIES

RELATIVES CONSENT FORM

Please work through the following statements and tick your responses. Please complete all parts of this form, including your signature.

I confirm that I am the relative of *(please print your relative's name below).*

…….. **YES [ ] NO [ ]**

I have been asked to agree to my relative's inclusion in a research project on injuries, accidents and falls in adults with learning disabilities.

I have been asked to participate with my relative, or give my consent for my relative and his/her support staff to participate, in a research interview about injuries, accidents and falls.

Participation in this project may ultimately help other people. It is unlikely to immediately help my relative.

The researchers will keep all information provided by my relative and me (or support staff) confidential and secure.

I have been given an information sheet about the project.

YES [ ] NO [ ]

I have asked all the questions I want to, and I know that I can ask the researcher further questions at any stage during the research project if I want to.

YES [ ] NO [ ]

I have been given enough answers to my questions, and I know that the researcher will answer any further questions that I may wish to ask.

YES [ ] NO [ ]

I know I can refuse if I want to, without having to give a reason why.

YES [ ] NO [ ]

If I refuse, I know it will not affect the future health care of my relative.

YES [ ] NO [ ]

If I agree, I know I can still change my mind and refuse at any stage during the research project.

YES [ ] NO [ ]

I know the researchers will write about the projects results. I know the researchers may include personal quotes in their results, but names will be changed and participants will remain anonymous.

YES [ ] NO [ ]

The project results will not include any identifiable information or our names. No one will be able to identify us, as information will be anonymised.

YES [ ] NO [ ]

I agree to take part with my relative, or give consent for my relative and his/her support staff to take part, in this research project.

YES [ ] NO [ ]

Your name ……

Your signature……

Date ……

Miss Janet Finlayson, Research Assistant, Section of Psychological Medicine, Division of Community Based Sciences, University of Glasgow, Academic Centre, Gartnavel Royal Hospital, 1055 Great Western Road, Glasgow G12 0XH. Telephone: 0141 211 0691. Email: jf96v@clinmed.gla.ac.uk. Fax: 0141 357 4899.

Appendix 6: Participant Consent Form

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INJURIES, ACCIDENTS AND FALLS IN ADULTS WITH LEARNING DISABILITIES

CONSENT FORM

***Please read each statement and tick your responses. Please complete all parts of this form, including your signature*.**

This form asks me if I will take part in a research project on injuries, accidents and falls.

This form asks me if I will agree to meeting a researcher to talk about my injuries, accidents and falls.

If I agree to take part, it will not immediately help me, but it may help other people with learning disabilities in the future.

The researchers will keep my information confidential (secret) and safe.

I have been given an information sheet about this research project.

YES [ ] NO [ ]

I have asked all the questions I want to, and I know I can ask more questions later on during the research study if I want to.

YES [ ] NO [ ]

I have been given enough answers to my questions, and I know the researcher will answer any other questions that I wish to ask later on during the research study.

YES [ ] NO [ ]

I know I can say no if I want to, without having to give a reason why. I do not have to take part in the research study. It is my choice.

YES [ ] NO [ ]

If I say no, I know it will not affect my future health care in any way.

YES [ ] NO [ ]

If I say yes just now, I know I can still change my mind and say no later on during the research project.

YES [ ] NO [ ]

I know the researchers will write about the project results. I know the researchers may include personal quotes (things I have said). I know that everything I say to the researcher will be anonymous.

YES [ ] NO [ ]

I know the project results will not include my name, address, date of birth, or any other identifiable details. No one will be able to identify me (know who I am) from the results.

YES [ ] NO [ ]

I agree to taking part in this research project YES [ ] NO [ ]

Your name ……

Your signature ……

Date ……

Witness name ……

Witness signature……

Date ……

Witness's relationship to participant ……

Miss Janet Finlayson, Research Assistant, Psychological Medicine, University of Glasgow, Academic Centre, Gartnavel Royal Hospital, 1055 Great Western Road, Glasgow, G12 0XH. Telephone: 0141 211 0691. Email: jf96v@clinmed.gla.ac.uk.

Appendix 7: Researcher Project Consent Statement Form

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Injuries, Accidents and Falls in Adults with Learning Disabilities

CONSENT STATEMENT FORM

I confirm that I have explained the research project as fully as possible, and answered all of the participant's questions.	**YES** ☐ **NO** ☐
I confirm that …….. has freely given consent to inclusion in the research project.	**YES** ☐ **NO** ☐
I confirm that …...…….. does not understand all details of the research project, but consents as far as she / he is able.	**YES** ☐ **NO** ☐
I confirm that …….. is not able to give or withhold consent to inclusion in the project.	**YES** ☐ **NO** ☐
For persons who do not have capacity to consent, I confirm that I have answered all of the welfare guardian's/relative's questions and that she/he has freely given consent to inclusion in the research project.	**YES** ☐ **NO** ☐

Signed …….

Name ……..……

Title ……

Date …… …

Appendix 8: Home Visit Research Interview Form (Questionnaire)

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Injuries, Accidents and Falls in Adults with Learning Disabilities

Home Visit Research Interview Form

Please us all of the examples given for questions as prompts

Section A: Participant's Injuries from Falls, Accidents and Harm

Please include medical attention or treatment from a nurse on site e.g. Nursing Home. Please include medical attention or treatment from a support worker (e.g. certified first aider) or a family carer (e.g. parent who is a nurse).

Falls

1. Please estimate how many times the person has fallen within the **last 12 months** (Please include falls that resulted from seizures). [ ] [ ]

   Or frequency, if more than 10 fall [ ] [ ] per week or [ ] [ ] per month

2. How many times has the person been injured, and received medical or nursing attention or treatment, as the result of a fall in the 12-month period? **[ ] [ ]***

Accidents

3. Please estimate how many times the person has had an accident within the **last 12 months**. (Exclude falls which have been counted in question 1). For example, road traffic accident; scalding; fire or chemical burns; poisoning e.g. wrong medication or food; choking on food or non-food items.

[ ] [ ]

Or frequency, if more than 10 accidents [ ] [ ] per week or [ ] [ ] per month

4. How many times has the person been injured, and received medical or nursing attention or treatment, as the result of an accident within the last 12 months?

[ ] [ ]*

Harm

5. Does the person live with another person/other people who has/have challenging or problem behaviours? (For example, physical aggression or destructiveness to property).

Yes [ ] No [ ] Don't know [ ]

Does the person come into contact with another person/other people who has/have challenging behaviour anywhere else, outwith his/her home? (For example, at a Day Centre or Respite Unit).

Yes. Please specify where…… [ ] No [ ] Don't know [ ]

If yes, please list the types of challenging behaviour that you are aware of the person being exposed to (Please use the list of problem behaviours from the C21st form to prompt the interviewee)……

6. If yes, how many times has the person been injured, and received medical attention or treatment, as the result of another person's/other people's challenging or problem behaviour in the **last 12 months**?

[ ] [ ]*

Self-Harm

7. How many times has the person been injured, and received medical attention or treatment, as a result of his/her own self-injurious behaviour/s in the **last 12 months**? **[ ] [ ]***

Person does not have self-injurious behaviour/s [ ]

8. How many times has the person been injured, and received medical attention or treatment, as a result of his/her other problem or challenging behaviour/s (other than self-injury) in the **last 12 months**? (For example, destructiveness to property and breaking glass objects). **[ ] [ ]***

Person does not have any other problem or challenging behaviours [ ]

**Please complete a Participant Description of Injuries Form for each injury that received medical attention or treatment reported.*

Please complete a maximum of 10 Participant Description of Injuries Forms only (for the 10 most recent injuries). All participants who exceed the maximum number of 10 injuries in the 12-month period will be offered a qualitative research interview by the principal investigator

Please skip to Page 13 if no falls, accidents, harm or self-harm identified

Section A continued: Participant Description of Injuries Form

1. Participant injury incident number: [ ] [ ] of [ ] [ ]

   Description of incident (accident/fall/injury). *Please include any causative factors/precipitants*……

   ……
   ……
   ……
   ……

2. Category of injury: [ ]

   Fall (seizure related) = 1; Fall (not seizure related = 2; Accident (other than a fall) = 3; Harm (problem behaviour/s of other/s) = 4; Self-harm (self-injurious behaviour) = 5; Self-harm (own problem behaviour/s other than self-injury) = 6.

3. Type of injury (or injuries, if more than one sustained at one time): [ ] [ ] [ ]

   Bruising = 1; Swelling = 2; Laceration (cut) = 3; Fracture = 4; Concussion = 5; Burns = 6; Poisoning = 7; Tooth or teeth damage = 8; Muscular or joint pain =9; Other. Please specify…….. = 10

4. Part (or parts) of body injured. Please specify…….

5. Where medical attention or treatment was sought: [ ]

   Accident & Emergency = 1; Own GP = 2; Primary Care Nurse from GP Surgery = 3; GEMS = 4; Dentist/Dental Hospital = 5; Nurse on site e.g. Nursing Home = 6; NHS24 = 7; Other. Please specify……..= 8.

6. Medical intervention/s: [ ] [ ] [ ] [ ]

   Hospital admission = 1; medical advice = 2; wound dressing (with stitches/sutures) = 3; wound dressing (without stitches/sutures) = 4; support bandage = 5; pain relief (medication) = 6; other medication (other than pain relief) = 7; operation = 8; limb/joint plaster (stookie) = 9; observation = 10; dental intervention = 11; Other. Please specify…… = 12.

7. Number of days spent in hospital: [ ] [ ] [ ]

8. Where person became injured (environment): [ ]

   At home = 1; At his/her work or Day Centre = 2; At a Respite Unit = 3; On holiday = 4; Outdoors, when out and about with a family member or friend = 5; Outdoors, when out and about with paid support = 6; Outdoors, when out and about unsupported (alone) = 7; Other. Please specify……..= 8.

9. Hazards identified? (Please specify e.g. kettle; stairs/steps; hot bath water; kitchen knife OR no hazards identified)…….

Section A continued: Participant Description of Injuries Form

1. Participant injury incident number: [ ] [ ] of [ ] [ ]

   Description of incident (accident/fall/injury). *Please include any causative factors/precipitants*……

   ……
   ……
   ……
   ……

2. Category of injury: [ ]

   Fall (seizure related) = 1; Fall (not seizure related = 2; Accident (other than a fall) = 3; Harm (problem behaviour/s of other/s) = 4; Self-harm (self-injurious behaviour) = 5; Self-harm (own problem behaviour/s other than self-injury) = 6.

3. Type of injury (or injuries, if more than one sustained at one time): [ ] [ ] [ ]

   Bruising = 1; Swelling = 2; Laceration (cut) = 3; Fracture = 4; Concussion = 5; Burns = 6; Poisoning = 7; Tooth or teeth damage = 8; Muscular or joint pain =9; Other. Please specify…….. = 10

4. Part (or parts) of body injured. Please specify…….

5. Where medical attention or treatment was sought: [ ]

   Accident & Emergency = 1; Own GP = 2; Primary Care Nurse from GP Surgery = 3; GEMS = 4; Dentist/Dental Hospital = 5; Nurse on site e.g. Nursing Home = 6; NHS24 = 7; Other. Please specify……..= 8.

6. Medical intervention/s: [ ] [ ] [ ] [ ]

   Hospital admission = 1; medical advice = 2; wound dressing (with stitches/sutures) = 3; wound dressing (without stitches/sutures) = 4; support bandage = 5; pain relief (medication) = 6; other medication (other than pain relief) = 7; operation = 8; limb/joint plaster (stookie) = 9; observation = 10; dental intervention = 11; Other. Please specify…… = 12.

7. Number of days spent in hospital: [ ] [ ] [ ]

8. Where person became injured (environment): [ ]

   At home = 1; At his/her work or Day Centre = 2; At a Respite Unit = 3; On holiday = 4; Outdoors, when out and about with a family member or friend = 5; Outdoors, when out and about with paid support = 6; Outdoors, when out and about unsupported (alone) = 7; Other. Please specify……..= 8.

9. Hazards identified? (Please specify e.g. kettle; stairs/steps; hot bath water; kitchen knife OR no hazards identified)…….

Section A continued: Participant Description of Injuries Form

1. Participant injury incident number: [ ] [ ] of [ ] [ ]

   Description of incident (accident/fall/injury). *Please include any causative factors/precipitants*……

   ……
   ……
   ……
   ……

2. Category of injury: [ ]

   Fall (seizure related) = 1; Fall (not seizure related = 2; Accident (other than a fall) = 3; Harm (problem behaviour/s of other/s) = 4; Self-harm (self-injurious behaviour) = 5; Self-harm (own problem behaviour/s other than self-injury) = 6.

3. Type of injury (or injuries, if more than one sustained at one time): [ ] [ ] [ ]

   Bruising = 1; Swelling = 2; Laceration (cut) = 3; Fracture = 4; Concussion = 5; Burns = 6; Poisoning = 7; Tooth or teeth damage = 8; Muscular or joint pain =9; Other. Please specify…….. = 10

4. Part (or parts) of body injured. Please specify…….

5. Where medical attention or treatment was sought: [ ]

   Accident & Emergency = 1; Own GP = 2; Primary Care Nurse from GP Surgery = 3; GEMS = 4; Dentist/Dental Hospital = 5; Nurse on site e.g. Nursing Home = 6; NHS24 = 7; Other. Please specify…….....= 8.

6. Medical intervention/s: [ ] [ ] [ ] [ ]

   Hospital admission = 1; medical advice = 2; wound dressing (with stitches/sutures) = 3; wound dressing (without stitches/sutures) = 4; support bandage = 5; pain relief (medication) = 6; other medication (other than pain relief) = 7; operation = 8; limb/joint plaster (stookie) = 9; observation = 10; dental intervention = 11; Other. Please specify……. = 12.

7. Number of days spent in hospital: [ ] [ ] [ ]

8. Where person became injured (environment): [ ]

   At home = 1; At his/her work or Day Centre = 2; At a Respite Unit = 3; On holiday = 4; Outdoors, when out and about with a family member or friend = 5; Outdoors, when out and about with paid support = 6; Outdoors, when out and about unsupported (alone) = 7; Other. Please specify……..……= 8.

9. Hazards identified? (Please specify e.g. kettle; stairs/steps; hot bath water; kitchen knife OR no hazards identified)…….

Section A continued: Participant Description of Injuries Form

1. Participant injury incident number: [ ] [ ] of [ ] [ ]

   Description of incident (accident/fall/injury). *Please include any causative factors/precipitants*……

   ……
   ……
   ……
   ……

2. Category of injury: [ ]

   Fall (seizure related) = 1; Fall (not seizure related = 2; Accident (other than a fall) = 3; Harm (problem behaviour/s of other/s) = 4; Self-harm (self-injurious behaviour) = 5; Self-harm (own problem behaviour/s other than self-injury) = 6.

3. Type of injury (or injuries, if more than one sustained at one time): [ ] [ ] [ ]

   Bruising = 1; Swelling = 2; Laceration (cut) = 3; Fracture = 4; Concussion = 5; Burns = 6; Poisoning = 7; Tooth or teeth damage = 8; Muscular or joint pain =9; Other. Please specify…….. = 10

4. Part (or parts) of body injured. Please specify…….

5. Where medical attention or treatment was sought: [ ]

   Accident & Emergency = 1; Own GP = 2; Primary Care Nurse from GP Surgery = 3; GEMS = 4; Dentist/Dental Hospital = 5; Nurse on site e.g. Nursing Home = 6; NHS24 = 7; Other. Please specify……..= 8.

6. Medical intervention/s: [ ] [ ] [ ] [ ]

   Hospital admission = 1; medical advice = 2; wound dressing (with stitches/sutures) = 3; wound dressing (without stitches/sutures) = 4; support bandage = 5; pain relief (medication) = 6; other medication (other than pain relief) = 7; operation = 8; limb/joint plaster (stookie) = 9; observation = 10; dental intervention = 11; Other. Please specify…… = 12.

7. Number of days spent in hospital: [ ] [ ] [ ]

8. Where person became injured (environment): [ ]

   At home = 1; At his/her work or Day Centre = 2; At a Respite Unit = 3; On holiday = 4; Outdoors, when out and about with a family member or friend = 5; Outdoors, when out and about with paid support = 6; Outdoors, when out and about unsupported (alone) = 7; Other. Please specify……..= 8.

9. Hazards identified? (Please specify e.g. kettle; stairs/steps; hot bath water; kitchen knife OR no hazards identified)……

Section A continued: Participant Description of Injuries Form

1. Participant injury incident number: [ ] [ ] of [ ] [ ]

   Description of incident (accident/fall/injury). *Please include any causative factors/precipitants*……

   ……
   ……
   ……
   ……

2. Category of injury: [ ]

   Fall (seizure related) = 1; Fall (not seizure related = 2; Accident (other than a fall) = 3; Harm (problem behaviour/s of other/s) = 4; Self-harm (self-injurious behaviour) = 5; Self-harm (own problem behaviour/s other than self-injury) = 6.

3. Type of injury (or injuries, if more than one sustained at one time): [ ] [ ] [ ]

   Bruising = 1; Swelling = 2; Laceration (cut) = 3; Fracture = 4; Concussion = 5; Burns = 6; Poisoning = 7; Tooth or teeth damage = 8; Muscular or joint pain =9; Other. Please specify…….. = 10

4. Part (or parts) of body injured. Please specify…….

5. Where medical attention or treatment was sought: [ ]

   Accident & Emergency = 1; Own GP = 2; Primary Care Nurse from GP Surgery = 3; GEMS = 4; Dentist/Dental Hospital = 5; Nurse on site e.g. Nursing Home = 6; NHS24 = 7; Other. Please specify……..= 8.

6. Medical intervention/s: [ ] [ ] [ ] [ ]

   Hospital admission = 1; medical advice = 2; wound dressing (with stitches/sutures) = 3; wound dressing (without stitches/sutures) = 4; support bandage = 5; pain relief (medication) = 6; other medication (other than pain relief) = 7; operation = 8; limb/joint plaster (stookie) = 9; observation = 10; dental intervention = 11; Other. Please specify…… = 12.

7. Number of days spent in hospital: [ ] [ ] [ ]

8. Where person became injured (environment): [ ]

   At home = 1; At his/her work or Day Centre = 2; At a Respite Unit = 3; On holiday = 4; Outdoors, when out and about with a family member or friend = 5; Outdoors, when out and about with paid support = 6; Outdoors, when out and about unsupported (alone) = 7; Other. Please specify……..= 8.

9. Hazards identified? (Please specify e.g. kettle; stairs/steps; hot bath water; kitchen knife OR no hazards identified)…….

Section A continued: Participant Description of Injuries Form

1. Participant injury incident number: [ ] [ ] of [ ] [ ]

   Description of incident (accident/fall/injury). *Please include any causative factors/precipitants*……

   ……
   ……
   ……
   ……

2. Category of injury: [ ]

   Fall (seizure related) = 1; Fall (not seizure related = 2; Accident (other than a fall) = 3; Harm (problem behaviour/s of other/s) = 4; Self-harm (self-injurious behaviour) = 5; Self-harm (own problem behaviour/s other than self-injury) = 6.

3. Type of injury (or injuries, if more than one sustained at one time): [ ] [ ] [ ]

   Bruising = 1; Swelling = 2; Laceration (cut) = 3; Fracture = 4; Concussion = 5; Burns = 6; Poisoning = 7; Tooth or teeth damage = 8; Muscular or joint pain =9; Other. Please specify…….. = 10

4. Part (or parts) of body injured. Please specify…….

5. Where medical attention or treatment was sought: [ ]

   Accident & Emergency = 1; Own GP = 2; Primary Care Nurse from GP Surgery = 3; GEMS = 4; Dentist/Dental Hospital = 5; Nurse on site e.g. Nursing Home = 6; NHS24 = 7; Other. Please specify……..= 8.

6. Medical intervention/s: [ ] [ ] [ ] [ ]

   Hospital admission = 1; medical advice = 2; wound dressing (with stitches/sutures) = 3; wound dressing (without stitches/sutures) = 4; support bandage = 5; pain relief (medication) = 6; other medication (other than pain relief) = 7; operation = 8; limb/joint plaster (stookie) = 9; observation = 10; dental intervention = 11; Other. Please specify…… = 12.

7. Number of days spent in hospital: [ ] [ ] [ ]

8. Where person became injured (environment): [ ]

   At home = 1; At his/her work or Day Centre = 2; At a Respite Unit = 3; On holiday = 4; Outdoors, when out and about with a family member or friend = 5; Outdoors, when out and about with paid support = 6; Outdoors, when out and about unsupported (alone) = 7; Other. Please specify……..= 8.

9. Hazards identified? (Please specify e.g. kettle; stairs/steps; hot bath water; kitchen knife OR no hazards identified)…….

Section A continued: Participant Description of Injuries Form

1. Participant injury incident number: [ ] [ ] of [ ] [ ]

   Description of incident (accident/fall/injury). *Please include any causative factors/precipitants*……

   ……
   ……
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   ……

2. Category of injury: [ ]

   Fall (seizure related) = 1; Fall (not seizure related = 2; Accident (other than a fall) = 3; Harm (problem behaviour/s of other/s) = 4; Self-harm (self-injurious behaviour) = 5; Self-harm (own problem behaviour/s other than self-injury) = 6.

3. Type of injury (or injuries, if more than one sustained at one time): [ ] [ ] [ ]

   Bruising = 1; Swelling = 2; Laceration (cut) = 3; Fracture = 4; Concussion = 5; Burns = 6; Poisoning = 7; Tooth or teeth damage = 8; Muscular or joint pain =9; Other. Please specify…….. = 10

4. Part (or parts) of body injured. Please specify…….

5. Where medical attention or treatment was sought: [ ]

   Accident & Emergency = 1; Own GP = 2; Primary Care Nurse from GP Surgery = 3; GEMS = 4; Dentist/Dental Hospital = 5; Nurse on site e.g. Nursing Home = 6; NHS24 = 7; Other. Please specify……..= 8.

6. Medical intervention/s: [ ] [ ] [ ] [ ]

   Hospital admission = 1; medical advice = 2; wound dressing (with stitches/sutures) = 3; wound dressing (without stitches/sutures) = 4; support bandage = 5; pain relief (medication) = 6; other medication (other than pain relief) = 7; operation = 8; limb/joint plaster (stookie) = 9; observation = 10; dental intervention = 11; Other. Please specify…… = 12.

7. Number of days spent in hospital: [ ] [ ] [ ]

8. Where person became injured (environment): [ ]

   At home = 1; At his/her work or Day Centre = 2; At a Respite Unit = 3; On holiday = 4; Outdoors, when out and about with a family member or friend = 5; Outdoors, when out and about with paid support = 6; Outdoors, when out and about unsupported (alone) = 7; Other. Please specify……..= 8.

9. Hazards identified? (Please specify e.g. kettle; stairs/steps; hot bath water; kitchen knife OR no hazards identified)……

Section A continued: Participant Description of Injuries Form

1. Participant injury incident number: [ ] [ ] of [ ] [ ]

   Description of incident (accident/fall/injury). *Please include any causative factors/precipitants*……

   ……
   ……
   ……
   ……

2. Category of injury: [ ]

   Fall (seizure related) = 1; Fall (not seizure related = 2; Accident (other than a fall) = 3; Harm (problem behaviour/s of other/s) = 4; Self-harm (self-injurious behaviour) = 5; Self-harm (own problem behaviour/s other than self-injury) = 6.

3. Type of injury (or injuries, if more than one sustained at one time): [ ] [ ] [ ]

   Bruising = 1; Swelling = 2; Laceration (cut) = 3; Fracture = 4; Concussion = 5; Burns = 6; Poisoning = 7; Tooth or teeth damage = 8; Muscular or joint pain =9; Other. Please specify…….. = 10

4. Part (or parts) of body injured. Please specify…….

5. Where medical attention or treatment was sought: [ ]

   Accident & Emergency = 1; Own GP = 2; Primary Care Nurse from GP Surgery = 3; GEMS = 4; Dentist/Dental Hospital = 5; Nurse on site e.g. Nursing Home = 6; NHS24 = 7; Other. Please specify……..= 8.

6. Medical intervention/s: [ ] [ ] [ ] [ ]

   Hospital admission = 1; medical advice = 2; wound dressing (with stitches/sutures) = 3; wound dressing (without stitches/sutures) = 4; support bandage = 5; pain relief (medication) = 6; other medication (other than pain relief) = 7; operation = 8; limb/joint plaster (stookie) = 9; observation = 10; dental intervention = 11; Other. Please specify…… = 12.

7. Number of days spent in hospital: [ ] [ ] [ ]

8. Where person became injured (environment): [ ]

   At home = 1; At his/her work or Day Centre = 2; At a Respite Unit = 3; On holiday = 4; Outdoors, when out and about with a family member or friend = 5; Outdoors, when out and about with paid support = 6; Outdoors, when out and about unsupported (alone) = 7; Other. Please specify……..= 8.

9. Hazards identified? (Please specify e.g. kettle; stairs/steps; hot bath water; kitchen knife OR no hazards identified)…….

Section A continued: Participant Description of Injuries Form

1. Participant injury incident number: [ ] [ ] of [ ] [ ]

   Description of incident (accident/fall/injury). *Please include any causative factors/precipitants*……

   ……
   ……
   ……
   ……

2. Category of injury: [ ]

   Fall (seizure related) = 1; Fall (not seizure related = 2; Accident (other than a fall) = 3; Harm (problem behaviour/s of other/s) = 4; Self-harm (self-injurious behaviour) = 5; Self-harm (own problem behaviour/s other than self-injury) = 6.

3. Type of injury (or injuries, if more than one sustained at one time): [ ] [ ] [ ]

   Bruising = 1; Swelling = 2; Laceration (cut) = 3; Fracture = 4; Concussion = 5; Burns = 6; Poisoning = 7; Tooth or teeth damage = 8; Muscular or joint pain =9; Other. Please specify…….. = 10

4. Part (or parts) of body injured. Please specify…….

5. Where medical attention or treatment was sought: [ ]

   Accident & Emergency = 1; Own GP = 2; Primary Care Nurse from GP Surgery = 3; GEMS = 4; Dentist/Dental Hospital = 5; Nurse on site e.g. Nursing Home = 6; NHS24 = 7; Other. Please specify……..= 8.

6. Medical intervention/s: [ ] [ ] [ ] [ ]

   Hospital admission = 1; medical advice = 2; wound dressing (with stitches/sutures) = 3; wound dressing (without stitches/sutures) = 4; support bandage = 5; pain relief (medication) = 6; other medication (other than pain relief) = 7; operation = 8; limb/joint plaster (stookie) = 9; observation = 10; dental intervention = 11; Other. Please specify…… = 12.

7. Number of days spent in hospital: [ ] [ ] [ ]

8. Where person became injured (environment): [ ]

   At home = 1; At his/her work or Day Centre = 2; At a Respite Unit = 3; On holiday = 4; Outdoors, when out and about with a family member or friend = 5; Outdoors, when out and about with paid support = 6; Outdoors, when out and about unsupported (alone) = 7; Other. Please specify……..= 8.

9. Hazards identified? (Please specify e.g. kettle; stairs/steps; hot bath water; kitchen knife OR no hazards identified)……

Section A continued: Participant Description of Injuries Form

1. Participant injury incident number: [ ] [ ] of [ ] [ ]

   Description of incident (accident/fall/injury). *Please include any causative factors/precipitants*……

   ……
   ……
   ……
   ……

2. Category of injury: [ ]

   Fall (seizure related) = 1; Fall (not seizure related = 2; Accident (other than a fall) = 3; Harm (problem behaviour/s of other/s) = 4; Self-harm (self-injurious behaviour) = 5; Self-harm (own problem behaviour/s other than self-injury) = 6.

3. Type of injury (or injuries, if more than one sustained at one time): [ ] [ ] [ ]

   Bruising = 1; Swelling = 2; Laceration (cut) = 3; Fracture = 4; Concussion = 5; Burns = 6; Poisoning = 7; Tooth or teeth damage = 8; Muscular or joint pain =9; Other. Please specify…….. = 10

4. Part (or parts) of body injured. Please specify…….

5. Where medical attention or treatment was sought: [ ]

   Accident & Emergency = 1; Own GP = 2; Primary Care Nurse from GP Surgery = 3; GEMS = 4; Dentist/Dental Hospital = 5; Nurse on site e.g. Nursing Home = 6; NHS24 = 7; Other. Please specify……..= 8.

6. Medical intervention/s: [ ] [ ] [ ] [ ]

   Hospital admission = 1; medical advice = 2; wound dressing (with stitches/sutures) = 3; wound dressing (without stitches/sutures) = 4; support bandage = 5; pain relief (medication) = 6; other medication (other than pain relief) = 7; operation = 8; limb/joint plaster (stookie) = 9; observation = 10; dental intervention = 11; Other. Please specify…… = 12.

7. Number of days spent in hospital: [ ] [ ] [ ]

8. Where person became injured (environment): [ ]

   At home = 1; At his/her work or Day Centre = 2; At a Respite Unit = 3; On holiday = 4; Outdoors, when out and about with a family member or friend = 5; Outdoors, when out and about with paid support = 6; Outdoors, when out and about unsupported (alone) = 7; Other. Please specify……..= 8.

9. Hazards identified? (Please specify e.g. kettle; stairs/steps; hot bath water; kitchen knife OR no hazards identified)……

Section B: Carer Comparison

Please ask the paid or unpaid carer the following questions.

1. What is your age? [ ][ ]

2. What is your gender? Male [ ] Female [ ]

3. What is your home post code? [ ][ ][ ][ ][ ][ ][ ]

4. How many times have **you** been injured, and received medical attention or treatment, as the result of a **fall** in the **last 12 months**?
[ ][ ]*

5. How many times have **you** been injured, and received medical attention or treatment, as the result of an **accident** (other than a fall) in the **last 12 months**?
[ ][ ]*

6. How many times have **you** been injured, and received medical attention or treatment, as the result of a **harmful action** (of self or others) in the **last 12 months**? **[ ][ ]***

**Please complete a Carer Description of Injuries Form for each injury that received medical attention or treatment reported.*

Please complete a maximum of 5 Carer Description of Injuries Forms only (for the 5 most recent injuries).

Please skip to Page 19 if none identified

Section B continued: Carer Description of Injuries Form

1. Carer injury incident number: [ ] [ ] of [ ] [ ]

   Description of incident (accident/fall/injury). *Please include any causative factors/precipitants*……
   ……
   ……
   ……

2. Category of injury: [ ]

   Fall (seizure related) = 1; Fall (not seizure related = 2; Accident (other than a fall) = 3; Harm (problem behaviour/s of other/s) = 4; Self-harm (self-injurious behaviour) = 5; Self-harm (own problem behaviour/s other than self-injury) = 6.

3. Type of injury (or injuries, if more than one sustained at one time): [ ] [ ] [ ]

   Bruising = 1; Swelling = 2; Laceration (cut) = 3; Fracture = 4; Concussion = 5; Burns = 6; Poisoning = 7; Tooth or teeth damage = 8; Muscular or joint pain =9; Other. Please specify……= 10.

4. Part (or parts) of body injured. Please specify…….

   ……

5. Where medical attention or treatment was sought: [ ]

   Accident & Emergency = 1; Own GP = 2; Primary Care Nurse from GP Surgery = 3; GEMS = 4; Dentist/Dental Hospital = 5; Nurse on site e.g. Nursing Home = 6; NHS24 = 7; Other. Please specify……...= 8.

6. Medical intervention/s: [ ] [ ] [ ] [ ]

   Hospital admission = 1; medical advice = 2; wound dressing (with stitches/sutures) = 3; wound dressing (without stitches/sutures) = 4; support bandage = 5; pain relief (medication) = 6; other medication (other than pain relief) = 7; operation = 8; limb/joint plaster (stookie) = 9; observation = 10; dental intervention = 11; Other. Please specify…….. = 12.

7. Number of days spent in hospital: [ ] [ ] [ ]

8. Where person became injured (environment): [ ]

   At home = 1; At his/her work or Day Centre = 2; At a Respite Unit = 3; On holiday = 4; Outdoors, when out and about with a family member or friend = 5; Outdoors, when out and about with paid support = 6; Outdoors, when out and about unsupported (alone) = 7; Other. Please specify……= 8.

9. Hazards identified? (Please specify e.g. kettle; stairs/steps; hot bath water; kitchen knife OR no hazards identified)…….

Section B continued: Carer Description of Injuries Form

1. Carer injury incident number: [ ] [ ] of [ ] [ ]

   Description of incident (accident/fall/injury). *Please include any causative factors/precipitants*……
   ……
   ……
   ……

2. Category of injury: [ ]

   Fall (seizure related) = 1; Fall (not seizure related = 2; Accident (other than a fall) = 3; Harm (problem behaviour/s of other/s) = 4; Self-harm (self-injurious behaviour) = 5; Self-harm (own problem behaviour/s other than self-injury) = 6.

3. Type of injury (or injuries, if more than one sustained at one time): [ ] [ ] [ ]

   Bruising = 1; Swelling = 2; Laceration (cut) = 3; Fracture = 4; Concussion = 5; Burns = 6; Poisoning = 7; Tooth or teeth damage = 8; Muscular or joint pain =9; Other. Please specify……= 10.

4. Part (or parts) of body injured. Please specify……

   ……

5. Where medical attention or treatment was sought: [ ]

   Accident & Emergency = 1; Own GP = 2; Primary Care Nurse from GP Surgery = 3; GEMS = 4; Dentist/Dental Hospital = 5; Nurse on site e.g. Nursing Home = 6; NHS24 = 7; Other. Please specify……= 8.

6. Medical intervention/s: [ ] [ ] [ ] [ ]

   Hospital admission = 1; medical advice = 2; wound dressing (with stitches/sutures) = 3; wound dressing (without stitches/sutures) = 4; support bandage = 5; pain relief (medication) = 6; other medication (other than pain relief) = 7; operation = 8; limb/joint plaster (stookie) = 9; observation = 10; dental intervention = 11; Other. Please specify…….. = 12.

7. Number of days spent in hospital: [ ] [ ] [ ]

8. Where person became injured (environment): [ ]

   At home = 1; At his/her work or Day Centre = 2; At a Respite Unit = 3; On holiday = 4; Outdoors, when out and about with a family member or friend = 5; Outdoors, when out and about with paid support = 6; Outdoors, when out and about unsupported (alone) = 7; Other. Please specify……= 8.

9. Hazards identified? (Please specify e.g. kettle; stairs/steps; hot bath water; kitchen knife OR no hazards identified)……

Section B continued: Carer Description of Injuries Form

1. Carer injury incident number: [ ] [ ] of [ ] [ ]

   Description of incident (accident/fall/injury). *Please include any causative factors/precipitants*……
   ……
   ……
   ……

2. Category of injury: [ ]

   Fall (seizure related) = 1; Fall (not seizure related = 2; Accident (other than a fall) = 3; Harm (problem behaviour/s of other/s) = 4; Self-harm (self-injurious behaviour) = 5; Self-harm (own problem behaviour/s other than self-injury) = 6.

3. Type of injury (or injuries, if more than one sustained at one time): [ ] [ ] [ ]

   Bruising = 1; Swelling = 2; Laceration (cut) = 3; Fracture = 4; Concussion = 5; Burns = 6; Poisoning = 7; Tooth or teeth damage = 8; Muscular or joint pain =9; Other. Please specify……= 10.

4. Part (or parts) of body injured. Please specify…….

   ……

5. Where medical attention or treatment was sought: [ ]

   Accident & Emergency = 1; Own GP = 2; Primary Care Nurse from GP Surgery = 3; GEMS = 4; Dentist/Dental Hospital = 5; Nurse on site e.g. Nursing Home = 6; NHS24 = 7; Other. Please specify……...= 8.

6. Medical intervention/s: [ ] [ ] [ ] [ ]

   Hospital admission = 1; medical advice = 2; wound dressing (with stitches/sutures) = 3; wound dressing (without stitches/sutures) = 4; support bandage = 5; pain relief (medication) = 6; other medication (other than pain relief) = 7; operation = 8; limb/joint plaster (stookie) = 9; observation = 10; dental intervention = 11; Other. Please specify…….. = 12.

7. Number of days spent in hospital: [ ] [ ] [ ]

8. Where person became injured (environment): [ ]

   At home = 1; At his/her work or Day Centre = 2; At a Respite Unit = 3; On holiday = 4; Outdoors, when out and about with a family member or friend = 5; Outdoors, when out and about with paid support = 6; Outdoors, when out and about unsupported (alone) = 7; Other. Please specify……= 8.

9. Hazards identified? (Please specify e.g. kettle; stairs/steps; hot bath water; kitchen knife OR no hazards identified)…….

Section B continued: Carer Description of Injuries Form

1. Carer injury incident number: [ ] [ ] of [ ] [ ]

   Description of incident (accident/fall/injury). *Please include any causative factors/precipitants*……
   ……
   ……
   ……

2. Category of injury: [ ]

   Fall (seizure related) = 1; Fall (not seizure related = 2; Accident (other than a fall) = 3; Harm (problem behaviour/s of other/s) = 4; Self-harm (self-injurious behaviour) = 5; Self-harm (own problem behaviour/s other than self-injury) = 6.

3. Type of injury (or injuries, if more than one sustained at one time): [ ] [ ] [ ]

   Bruising = 1; Swelling = 2; Laceration (cut) = 3; Fracture = 4; Concussion = 5; Burns = 6; Poisoning = 7; Tooth or teeth damage = 8; Muscular or joint pain =9; Other. Please specify……= 10.

4. Part (or parts) of body injured. Please specify..……

   ……

5. Where medical attention or treatment was sought: [ ]

   Accident & Emergency = 1; Own GP = 2; Primary Care Nurse from GP Surgery = 3; GEMS = 4; Dentist/Dental Hospital = 5; Nurse on site e.g. Nursing Home = 6; NHS24 = 7; Other. Please specify……= 8.

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   Hospital admission = 1; medical advice = 2; wound dressing (with stitches/sutures) = 3; wound dressing (without stitches/sutures) = 4; support bandage = 5; pain relief (medication) = 6; other medication (other than pain relief) = 7; operation = 8; limb/joint plaster (stookie) = 9; observation = 10; dental intervention = 11; Other. Please specify…….. = 12.

7. Number of days spent in hospital: [ ] [ ] [ ]

8. Where person became injured (environment): [ ]

   At home = 1; At his/her work or Day Centre = 2; At a Respite Unit = 3; On holiday = 4; Outdoors, when out and about with a family member or friend = 5; Outdoors, when out and about with paid support = 6; Outdoors, when out and about unsupported (alone) = 7; Other. Please specify……= 8.

9. Hazards identified? (Please specify e.g. kettle; stairs/steps; hot bath water; kitchen knife OR no hazards identified)……

Section B continued: Carer Description of Injuries Form

1. Carer injury incident number: [ ] [ ] of [ ] [ ]

   Description of incident (accident/fall/injury). *Please include any causative factors/precipitants*……
   ……
   ……
   ……

2. Category of injury: [ ]

   Fall (seizure related) = 1; Fall (not seizure related = 2; Accident (other than a fall) = 3; Harm (problem behaviour/s of other/s) = 4; Self-harm (self-injurious behaviour) = 5; Self-harm (own problem behaviour/s other than self-injury) = 6.

3. Type of injury (or injuries, if more than one sustained at one time): [ ] [ ] [ ]

   Bruising = 1; Swelling = 2; Laceration (cut) = 3; Fracture = 4; Concussion = 5; Burns = 6; Poisoning = 7; Tooth or teeth damage = 8; Muscular or joint pain =9; Other. Please specify……= 10.

4. Part (or parts) of body injured. Please specify……..

   ……..

5. Where medical attention or treatment was sought: [ ]

   Accident & Emergency = 1; Own GP = 2; Primary Care Nurse from GP Surgery = 3; GEMS = 4; Dentist/Dental Hospital = 5; Nurse on site e.g. Nursing Home = 6; NHS24 = 7; Other. Please specify……= 8.

6. Medical intervention/s: [ ] [ ] [ ] [ ]

   Hospital admission = 1; medical advice = 2; wound dressing (with stitches/sutures) = 3; wound dressing (without stitches/sutures) = 4; support bandage = 5; pain relief (medication) = 6; other medication (other than pain relief) = 7; operation = 8; limb/joint plaster (stookie) = 9; observation = 10; dental intervention = 11; Other. Please specify…….. = 12.

7. Number of days spent in hospital: [ ] [ ] [ ]

8. Where person became injured (environment): [ ]

   At home = 1; At his/her work or Day Centre = 2; At a Respite Unit = 3; On holiday = 4; Outdoors, when out and about with a family member or friend = 5; Outdoors, when out and about with paid support = 6; Outdoors, when out and about unsupported (alone) = 7; Other. Please specify……= 8.

9. Hazards identified? (Please specify e.g. kettle; stairs/steps; hot bath water; kitchen knife OR no hazards identified)……

Section C: About Special Aids and Adaptions

1. Do you have any special flooring/carpeting in place at home for your relative/the person you support, to help prevent injuries? (E.g. non-slip mats or cushioned flooring). Yes [ ] No [ ] Not required [ ]

   If **yes**, please specify ……

2. Do you have any special lifting aids in place at home for your relative/the person you support, to help prevent injuries? (E.g. hoist). Yes [ ] No [ ] Not required [ ]

   If **yes**, please specify……

3. Do you have any special alarms in place at home for your relative/the person you support, to help prevent injuries? (E.g. epilepsy alarm; door alarm; smoke alarm; pressure mat alarm; emergency alert button/cord). Yes [ ] No [ ] Not required [ ]

   If **yes**, please specify……

4. Does your relative/the person you support have any special body protective equipment, to help prevent injuries? (E.g. epilepsy helmet; hip protectors; wrist protectors). Yes [ ] No [ ] Not required [ ]

   If **yes**, please specify……

5. Do you have any special bathroom aids in place at home for your relative/the person you support, to help prevent injuries? (E.g. temperature controlled hot water or shower seat). Yes [ ] No [ ] Not required [ ]

   If **yes**, please specify……

6. Do you have any special bedroom equipment in place at home for your relative/the person you support, to help prevent injuries? (E.g. bed sides).

   Yes [ ] No [ ] Not required [ ]

   If **yes**, please specify……

7. Do you have any special kitchen equipment in place at home for your relative/the person you support, to help prevent injuries? (E.g. safety or childproof locks on cupboards). Yes [ ] No [ ] Not required [ ]

   If **yes**, please specify……

8. Does the property have any special outdoor/garden equipment in place for your relative/the person you support, to help prevent injuries? (E.g. ramp or hand rails). Yes [ ] No [ ] Not required [ ]

   If **yes**, please specify……

9. Additional aids and adaptions not already mentioned ……

   ……

Section D: About Risk Assessments

*Please complete this section with **paid carers** i.e. support workers only.*

This section refers to formal (written) risk assessments only. (The risk assessments may be incorporated into the person's individual support plan, but notes in his/her daily diary/log only e.g. brief summaries of appointments with health care professionals are not accepted as such).

1. Have you and your staff team carried out any **individual** (or individualized) risk assessments for the person you support at any time? (For example, person's road safety awareness; person's personal hygiene, such as showering or bathing; person's risk of falling; person's ability to travel on public transport; person's support level needs; support staff's responses to person's challenging behaviour; kitchen safety; bathroom safety; garden safety). Yes [ ] No [ ] Don't know [ ]

   If **yes**, please list separately all areas of risk assessment that was carried out for the person ……..

   …….

   Have you and your staff team reviewed any of these risk assessments within the **last 12 months**? Yes [ ] No [ ] Don't know [ ]

2. Have you ever received any training on risk assessments, or how to carry out risk assessments? Yes [ ] No [ ] Don't know [ ]

   If **yes**, during what training? Please give details ……

   ……..

3. Please provide a brief description of:

   how injuries, accidents and falls are recorded/documented (e.g. accident or incident forms);

   who gets notified (e.g. immediate line manager; middle or senior organisational manager; care manager; GP; relatives); and

   whether or not there are systems in place for reviewing/investigating after there has been an accident.

   Any modifications/changes (e.g. physical changes to house, supports, or changes in practice/procedures made following the injury/fall/accident).

   …….

   …….

   …….

   …….

Section E: Mobility

1. What type of support, if any, does the person require with regards to mobility?

Walks independently [ ]

Walking stick [ ]

Walking frame/zimmer [ ]

Wheelchair (outdoors only) [ ]

Wheelchair (outdoors and indoors) [ ]

Other. Please state. [ ]

……

2. Does your relative/the person you support have either poor balance or coordination?

No, neither [ ] Yes, both [ ] Yes, poor balance [ ] Yes, poor coordination [ ]

3. Does your relative/the person have a tendency to be either restless or impatient?

No, neither [ ] Yes, both [ ] Yes, restless [ ] Yes, impatient [ ]

Section F: Carer's Thoughts on Accidental Injuries and Falls

Please ask the paid or unpaid carer how strongly he/she agrees or disagrees with the following statements. (You can hand the lists of statements to the carer to complete on his/her own if you or he/she prefer).

1. People with learning disabilities are more prone to falling than other people, when compared with the general population.
   Strongly agree [ ] Agree [ ] Don't know [ ] Disagree [ ] Strongly disagree [ ]

2. People with learning disabilities are more likely to have accidents and become injured than other people, when compared with the general population.
   Strongly agree [ ] Agree [ ] Don't know [ ] Disagree [ ] Strongly disagree [ ]

3. My relative/the person I support has a fear of falling.
   Strongly agree [ ] Agree [ ] Don't know [ ] Disagree [ ] Strongly disagree [ ]

4. My relative/the person I support is either clumsy or accident-prone.
   Strongly agree [ ] Agree [ ] Don't know [ ] Disagree [ ] Strongly disagree [ ]

5. Most accidents are preventable.
   Strongly agree [ ] Agree [ ] Don't know [ ] Disagree [ ] Strongly disagree [ ]

6. If your relative/the person you support **has** fallen within the **last 12 months**, do you think he/she is more likely to fall at a particular time of year? (For example, in the Summer due to being more active, or in the Winter due to weather conditions).

   Yes, during Spring/Summer [ ]

   Yes, during Autumn/Winter [ ]

   No [ ]

   Don't know [ ]

   Person has not fallen [ ]

Do you have any additional comments that you would like to make?

……
……
……
……
……

Would you like us to send you a summary of the results of this study when it is complete?

Yes [ ] No [ ]

Thank you for taking the time to answer these questions

Appendix 9: Demographic questions extracted from the T2 data collection instrument for the larger study this PhD researcher project was built on to

DEMOGRAPHICS

Date of birth (date/month/year)

[ ][ ] / [ ][ ] / [ ][ ]

Gender

Male = 1; Female = 2

[ ]

Marital status

Married/live-in partner = 1; Separated/divorced = 2; Single = 3; Widow/er = 4

[ ]

Ethnicity

Indian = 1; Pakistani = 2; Bangladeshi = 3; Chinese = 4; Caucasian = 5; Black Caribbean = 6; Black African = 7; Black other = 8; Other = 9 & specify……[ ]

Postcode ……

SOCIAL SUPPORTS

Who does the person live with?

Lives alone = 1; Lives with partner = 2; Lives with parent/s = 3; Lives with other family carer = 4; Lives with other person/people = 5; Other = 6 & specify ……

[ ]

Type of accommodation:

Parental home = 1; Other family carer home = 2; Lives independently = 3; Lives independently with spouse/partner = 4; Supported group living = 5; Supported living – individual = 6; Residential care = 7; Nursing home = 8; NHS accommodation = 9; Other = 10 & specify …….....

[ ]

Appendix 10: SHS 2003 Types and Causes of Injury General Population Data

SHS 2003 Categories:	**Scottish General Population (16 years and over) N = 8, 148 (100%)**	**Scottish General Population (18 – 64 years) N = 6, 014 (100%)**
Type of injury:		
Broken bones	161 (2.0%)	104 (1.7%)
Dislocated joints	35 (0.4%)	26 (0.4%)
Losing consciousness	47 (0.6%)	32 (0.5%)
Straining/twisting part of body	295 (3.6%)	245 (4.0%)
Cutting/grazing part of body	254 (3.1%)	182 (3.0%)
Bruising/pinching part of body	317 (3.9%)	224 (3.7%)
Object stuck in part of body	41 (0.5%)	34 (0.6%)
Burning or scalding	25 (0.3%)	20 (0.3%)
Poisoning	9 (0.1%)	8 (0.1%)
Internal injury	22 (0.3%)	18 (0.3%)
Animal/insect bite or sting	13 (0.2%)	13 (0.2%)
Swelling or tenderness	354 (4.2%)	262 (4.4%)
Other type/s (unspecified)	26 (0.3%)	20 (0.3%)
Cause of injury:		
Fall, trip or slip	448 (5.5%)	271 (4.5%)
Hit by a falling object	29 (0.3%)	25 (0.4%)
Road traffic accident	63 (0.8%)	50 (0.8%)
Sports/recreational accident	90 (1.5%)	81 (1.3%)
Use of tool/implement/equipment	123 (1.5%)	107 (1.8%)
Burn or scald	21 (0.2%)	19 (0.3%)
Animal/insect bite or sting	22 (0.2%)	19 (0.3%)
Another person (e.g. attacks)	46 (0.5%)	42 (0.7%)
Lifting	28 (0.3%)	25 (0.4%)
Other cause/s (unspecified)	0 (0%)	0 (0%)

Source: Scottish Health Survey 2003 (Scottish Executive, 2005).